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ABSTRACT

Fourteen papers examine current issues and practices in the education of students with severe mental retardation (SMR). Papers touch upon the broad context of education for SMR students, programs for the SMR population, and critical issues. The following papers are presented: "The Severely Mentally Retarded Individual: Philosophical and Implementarion Dilemmas" (D. Bricker and J. Filler); "Educational Policy and Severe Mental Retardation" (M. Noel, P. Burke, and C. Valdivieso); "Judicial Address of Education for Students with Severe Mental Retardation: From Access to Schools to State-of-the Art" (F. Laski); "Severely Mentally Retarded Young Children" (D. Gentry and J. Olson); "Educational Programs for Severely Mentally Retarded Elementary-Age Children: Progress, Problems, and Suggestions" (J. Tawney and K. Sniezek); "Programs for Secondary-Age Severely Handicapped Youth" (W. Williams, R. Vogelsberg, and R. Schutz); "Programs for Severely Mentally Retarded Adults: Perspectives and Methodologies" (F. Rusch J. Chadsey-Rusch, D. White, and J. Gifford); "Parents/Families of Persons with Severe Mental Retardation" (B. Fredericks); "The Evaluation of Severely Mentally Retarded Populations" (O. White); "Integration Efforts for Students with Severe Mental Retardation" (R. Gaylord-Ross and C. Peck); "Curricula without Recipes: A Challenge to Teachers and a Promise to Severely Mentally Retarded Students" (R. Brinker); "Behavioral Control and Education of Severely Handicapped Students: Who's Doing What to Whom? and Why?" (D. Guess and E. Siegel-Causey); "The Consequences of Bias in Studies of Living Arrangements for the Mentally Retarded Adult" (E. Butterfield); and "Perspectives on Methodological and Research Issues Concerning Severely Mentally Retarded Persons" (H. Switzky and H. Haywood). (CL)

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SEVERE MENTAL RETARDATION:

FROM THEORY TO PRACTICE

Edited by

Diane Bricker
John Filler

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The content of individual publications reflects the views of its editor(s) and/or author(s) and does not necessarily represent official positions of the Division or its governing members.

It is hoped that the quality and utility of these publications will encourage their use and adoption by school system personnel, college and university instructors, and administrators and staff of public and private agencies serving the needs of the mentally retarded.

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DEDICATION

The editors of this volume were privileged to be first students and then colleagues of Nicholas Hobbs during their days at Peabody College in the early 70s. His influence on us and others locally, nationally and internationally was enormous. His death brings both a personal and professional loss. The changes he orchestrated in our national approach and policy towards children and families leaves a legacy that will enhance future efforts for those most in need—the poor, the handicapped and the ill. In that sense of striving to formulate more humane and effective programs, this volume is dedicated to Nick.

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FOREWORD

NORRIS G. HARING

In 1977, the Division on Mental Retardation of the Council for Exceptional Children published a volume, conceived and edited by Ed Sontag, entitled "Educational Programming for the Severely and Profoundly Handicapped." This volume has been one of the most widely disseminated and influential works of its kind in the history of special education. Now, some seven years hence, the Division has sponsored another volume designed to select, accumulate, review, analyze, and translate research from special education and applied psychology into knowledge and strategies for the practitioner involved in educating severely mentally retarded persons. This effort will certainly enhance the effectiveness of professionals working toward increasing the quality of life, extent of productivity, and independence of severely handicapped individuals.

We have seen many impressive demonstrations of what the combined forces of federal, state, and local education agencies can achieve when the motivation for cooperation is present. An excellent example of this is the Handicapped Children's Early Education Program (HCEEP), founded in 1969 and administered by the Bureau of Education for the Handicapped (now Special Education Programs). This program has played a significant role in influencing programs for handicapped infants and young children. HCEEP's success can be gauged by the enormous influence its programs have had in stimulating states and local districts throughout the nation to begin serving handicapped and at-risk infants and preschool children. There are now 14 states which mandate education from birth, and the majority of other states are complying with the education from age three mandate of P.L. 94-142. Productive research efforts have begun with funding provided by the Special Education Programs for the four Early Childhood Research Institutes at the Educational Testing Service, the University of California at Los Angeles, the University of Kansas, and the University of North Carolina. Through research from these previously funded institutes and their newly funded counterparts, an increasing amount of information is being gained in the areas of screening, assessment, effective intervention, and learning strategies.

There are many examples of the significant gains achieved through cooperative efforts since 1977. Among the most impressive are the research activities in intervention with the severely handicapped student involving integration of these individuals with their nonhandicapped peers. The parents of some handicapped students have expressed concern as projects in local schools proceed to place severely handicapped students in regular, integrated elementary and secondary facilities with the result that many segregated special schools have been closed. Most of these integration projects report encouraging results where proper administrative planning and systematic instructional programming have accompanied the integration plan.

This volume presents a variety of research perspectives, and includes the work of 27 of the most talented researchers and authors who serve the handicapped as educators and advocates. A comprehensive study of 14 school districts throughout the United States done to evaluate the effectiveness of integration is described. Another excellent study by Voeltz showed that handicapped individuals who were integrated had significantly higher levels of acceptance among the nonhandicapped. An excellent summary and discussion of research on integration of the handicapped can be found in the Gaylord-Ross and Peck chapter.

Continuing with identifying some substantial recent refinements of our technology of teaching the severely handicapped, several chapters in this volume raise critical questions about instructional dependency, and the failure to fade instructional cues to the natural environment. Such questions are prompting researchers to expand their ideas about when learning has been completed. We have found that the acquisition of skills does not assure us that the individual can apply those skills in natural settings. We have seen that several important stages of learning follow acquisition. These are maintenance, generalization, and adaptation.

Another rich vein of discovery has come from research on peer initiation with severely retarded individuals. The results at all age levels support the value of social interaction with the nonhandicapped for improving social skills among the severely handicapped. While the value of integrated educational placements is still strongly questioned by some, even those who resist will have to admit to the accumulating evidence of significant gains in social development demonstrated by severely handicapped persons who are being educated in an integrated setting.

Among the most significant results of recent empirical studies in the education of these individuals is the emphasis on community-based instruction. As we move toward the last phase of mandated educational provisions, the ultimate success of public education in facilitating adaptation to the community is being tested. *In vivo* training as a prelude to transition has obvious advantages. It provides many variables that are in the natural setting and "it ensures that the clusters of related skills are taught instead of focusing on isolated skills."

How well our handicapped adults perform in communities is a real test of the training efforts that have preceded adulthood. But to believe that training and adaptive processing can be discontinued at given times in the life of the handicapped is naive. Effective integration is an ongoing process, and the big problem in our society is that state agencies responsible for community integration are finding it very difficult to work together effectively to achieve common goals.

Professionals working with severely handicapped persons should take advantage of the fact that the major share of the applied research with severely handicapped persons has been conducted in recent years. Some of the most important results and the implications of these results are reported in this volume. But this book goes further in several instances. A good example of this can be seen in the Guess and Siegel-Causey chapter, if I may close with a quotation to emphasize the point:

> It is our position that *technicians* can be taught to follow carefully prescribed instructional programs. With instruction, technicians can be prepared to systematically and accurately move a severely handicapped learner toward successful completion of an identified educational objective. It is a *teacher*, however, who can provide a broader approach to the educational process by modifying the instructional environment to enhance untargeted emerging skills that demonstrate movement toward more complex and adaptive levels of functioning.

SECTION ONE/
INTRODUCTION

CHAPTER 1/
THE SEVERELY MENTALLY RETARDED INDIVIDUAL: PHILOSOPHICAL AND IMPLEMENTATION DILEMMAS

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Definitional issues
Personnel preparation
Appropriate education
Service delivery systems
From research to practice
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INTRODUCTION

The provision of services beyond custodial care to the severely mentally retarded individual is a relatively new venture and we therefore find ourselves on the threshold of making a number of decisions that will impact the field today and for years to come. Further, the trends and strategies developed for the more severely impaired individual may have the potential for affecting improvement in services for the more mildly handicapped and perhaps the nonhandicapped as well (Bricker, Bruder, & Bailey, 1982). Because decisions made today in the field of the severely mentally retarded will directly and indirectly impact the future of special education, a significant responsibility exists to thoughtfully consider and examine the procedures and approaches that have been tried. The purpose of this volume is to do just that. Each contributor was asked to review a decade of the most pertinent and influential findings of his/her assigned topic, and then to critique this information base. These critiques highlight areas where progress has been made and those areas where future efforts should be concentrated.

As a foundation for the subsequent chapters contained in this volume, a brief discussion of the major and pervasive issues surrounding the severely mentally retarded population is offered. These issues include: 1) population definition; 2) personnel preparation; 3) parameters of appropriate education; 4) service delivery approaches; and 5) translation of research findings to practice.

Definitional Issues

Why spend time worrying about definitions when resources might be more effectively deployed to develop new and better service delivery strategies? To be sure, current definitions seem to have little bearing upon the quality of service programs offered the handicapped individual. Defining a child as retarded does not tell a teacher what the content of instruction should be. However, current federal and state laws and policy definitions do provide the bases for the placement of individuals into specific programs and the generation of support for those individuals.

As Nick Hobbs once observed, only the romantic think we can do away with labels or categories and thus definitions. Like it or not our service delivery systems demand that we have mechanisms for assigning individuals to programs. Currently the allocation of most resources for programs and individuals is based on categorical definitions and for this reason it is important to note what definitions of retardation entail.

According to the American Association on Mental Deficiency (Grossman, 1973), the American Psychiatric Association (DSM, 1980), the World Health Organization (1968) and the laws of most of our states and territories, a mentally retarded person is one who exhibits a significant (greater than two standard deviations below the mean) impairment in measured intelligence and exhibits an accompanying impairment in adaptive behavior, both of which are apparent during the developmental period (the first 18 years of life). The terms *mild, moderate, severe and profound* retardation refer to degree of retardation and are assigned based on the score obtained on an intelligence test. Accordingly, a severely retarded person is one whose condition arose during the developmental period, has an impairment in adaptive behavior and has obtained a score on an IQ test which falls between 4 and 5 standard deviations below the mean of the particular test employed. A profoundly retarded person would be one who is retarded but whose obtained IQ score falls at least 5 standard deviations below the mean of the test administered. Such definitions of severe and profound retardation are purely statistical because they are based exclusively on scores obtained on IQ tests. While these definitions are not, nor were they ever intended to be, used as a criterion for admission to categorical services, they do provide adequate parameters for establishing the focal population of this volume. Thus in this volume all retarded individuals whose performance yields an IQ score more than 4 standard deviations below the mean on a standardized IQ test will be categorized as severely retarded. Generally no distinction is made by authors between severely or profoundly retarded unless specifically noted.

A further word regarding definition of the population is necessitated by the currently popular usage of the term *severely handicapped*. The reader will note that the terms severely retarded and severely handicapped are often used interchangeably within and across chapters. The interchangeability of these terms occurs because most of the numerous definitions of severely handicapped which have been advanced since 1975 have included severe and profound retardation (see Fewell & Cone, 1983 for a review). The numerous recent definitions stress that a common characteristic of all severely handicapped individuals is severe intellectual impairment (see for example: Brown, Ford, Nisbet, Sweet, Donnellan, & Gruenewald, 1983; Sailor & Guess, 1983). Thus, whenever the reader encounters the term severely handicapped the author(s) is referring to severely retarded individuals whose retardation may exist either singularly or in consort with one or more other handicapping conditions.

Personnel Preparation

The quality of programs and services for the severely retarded population appear to be directly dependent upon the quality of the personnel providing the services. Issues surrounding personnel preparation are addressed by a number of the chapters in this volume and the consensus appears to be that the field falls short of being able to produce teachers, supervisors, and therapists that can consistently bring about desired outcomes in the target population.

Pioneers in the area of the severely handicapped have spent considerable time and effort in the development of personnel preparation programs for teachers and others destined to work with the severely retarded. Major support from the Office of Special Education and Rehabilitative Services has been available during the past 10 years and yet one can find few, if any, empirical investigations of the impact of the personnel preparation programs on change in the target population. This is not meant to be critical of the many efforts designed to train personnel; rather it is to inject a word of caution about the known impact of trained personnel on children and adults that are severely retarded. There appears to be a tacit assumption that if trainees acquire the competencies specified in a training program they will, in fact, become effective interventionists. What we do not yet know is whether the acquisition of the selected competencies does result in skillful and effective interventionists or whether, in fact, critical elements or features are missing. In this volume the Guess and Siegel-Causey chapter addresses a number of critical issues surrounding current approaches to personnel preparation programs. Likewise the chapter by Brinker discusses present approaches to teacher training and curricular efforts and suggests that a reevaluation of training and curricular strategies is necessary

A second issue raised by a number of authors is the lack of personnel to manage adult clients. The Williams, Vogelsburg and Schutz chapter, the Rusch, Chadsey, White and Gifford chapter, as well as the chapter by Fredericks, underline the lack of personnel who are specifically trained to deal with secondary and adult severely retarded students. Although the demands for service to this older population are unique, many personnel preparation programs appear not to make relevant distinctions in the program content offered to their trainees and specific certification for teachers of the secondary or adult student is rare. The increasing push for ecologically sound training demands an associated shift in training emphasis for students planning to work with secondary and adult populations.

Another dilemma facing personnel and parents working with the severely retarded concerns expectations. Recent advances have encouraged the field to oppose the standard of expecting little or nothing from the severely retarded population. This reaction has potential for producing unreasonable expectations of progress that may be equally damaging for interventionists, parents and retarded individuals. Indeed what should parents, interventionists and the general public expect from this population? Given current knowledge and technology we face significant limitations in helping the severely retarded population as a whole achieve normalcy. This reality should not dilute the progress that has been made nor divert the continued work to assist in expanding the potential of this population.

Appropriate Education

As Noel, Burke and Valdivieso point out, P.L. 94-142 has provided a mandate for the provision of a free, appropriate education for every handicapped school-age child that has had a significant impact at the state and local level. Action is clearly underway to expand the provision of appropriate services to preschool and adult severely handicapped individuals. As the Laski chapter indicates a major dilemma looming on the horizon is the nature or definition of "appropriate education" for not only the school-age but preschool and adult populations as well.

It would seem that the delivery of an appropriate education is based on the assumption that educators and other allied health specialists can specify a "longitudinal curriculum" that leads to maximum change and growth for every individual. Yet as Tawney and Sniezek point out the specification of such a curriculum or appropriate educational content becomes a complex task when dealing with a severely retarded student. Ideally, one would like to select a set of objectives just as one does for a nonhandicapped population. For example, educational objectives for a nonhandicapped 4th grader might include reading at grade level, and mathematical computation at grade level. Once such objectives or normative standards are set, the instructional content can be organized to insure the acquisition of those objectives—which in effect operationally defines an appropriate education. Such relatively precise statements about the content of an appropriate education are currently difficult to generate for the severely retarded population. The heterogeneity represented in this population precludes the establishment of a standard set of content as might be possible for nonhandicapped 4th graders. Even so, Laski points out that courts are clearly moving to establish the parameters of an appropriate education for the severely handicapped population.

Great caution must be exercised or the courts may lead us into decisions that render training efforts less rather than more appropriate. The dilemma facing the field is to set standards that assure quality while allowing for the necessary flexibility to accommodate the diversity found within the population.

Service Delivery Systems

The primary issues surrounding service delivery to the severely mentally retarded as with all severely handicapped populations focus on where and how to maintain them in the least restrictive environment. Most professionals, parents and laymen could probably agree with placement of the retarded individual in the least restrictive environment. However, in the Butterfield chapter the lack of objective analysis in determining the impact of various living arrangements on mentally retarded populations is addressed. Given the abundant rhetoric concerning the mentally retarded individual's placement for training and living, the lack of information documenting the impact of various arrangements is unsettling. It may be that issues surrounding least restrictive environments are socio-political problems first and empirical questions second. If so, some agreement should be reached so that empirical efforts can be directed toward determining the most useful methods of education and training within the agreed upon environment. On the other hand, if placement for education and living is determined to be an empirical issue, then we must begin to conduct comparative studies of the nature recommended by Butterfield.

A major feature of placing retarded individuals in least restrictive environments is the access to nonretarded people. Said another way what is the effect of integrating severely retarded individuals with the nonretarded? The number of studies examining this area certainly exceed those addressing the impact of living arrangements. Gaylord-Ross and Peck review the most pertinent literature on integration. Their conclusions are important. First, they suggest that the general outcomes of integration can be positive for the handicapped as well as the nonhandicapped person involved in the program; however, the success of integration efforts appears to be dependent upon the quality of the services delivered. Placing severely handicapped individuals in situations with nonhandicapped persons will not automatically yield "happy" outcomes. Planning and careful execution are probably largely responsible for the quality of the experiences for both the handicapped and nonhandicapped participants. Arbitrary dumping of severely retarded children or adults into situations with their nonhandicapped counterparts will most likely produce attitudes and interactions that run counter to the goal of school/community integration.

For a number of years many specialists in the area of the severely handicapped have argued for the inclusion of this population within the framework of public education. Bringing the severely handicapped into the "mainstream" of public education has been a major accomplishment. The nature of severely handicapped inclusion has mirrored the general procedures used for most other school children. That is, you come to school from 8 to 3, sit at a desk, and complete assigned tasks. The adequacy of this model for the severely mentally retarded is of serious concern. For example, Gentry and Olson allude to changes in intervention strategies for the handicapped infant and young child. The focus of training is shifting from the child to the caregiver and the targets are being embedded in the daily activities of the youngsters. One-to-one tutorials in which tight behavioral control is established is being replaced by equally rigorous behavioral strategies that embed training on specific behavioral targets into the child's daily tasks or activities. Thus language training occurs when the infant points and requests a desired object rather than during a specific time during the day designated as "language time." Williams, Vogelsburg, and Schutz make a similar point about training for the secondary students. They make a strong case for the need to shift training to the community or actual work or living environments if the training impact is to be maximized. Perhaps this shift in service delivery models is most apparent for the adult population. Rusch and his colleagues advocate an approach that takes into account the retarded individual's perspective as well as the perspectives of other individuals who are part of the handicapped person's social context. It seems obvious that for successful training and living arrangements to become a reality, the field must address the larger ecological context into which the handicapped individual will be placed.

From Research to Practice

The contributors to this volume have made a conscientious effort to identify, whenever possible, the body of research upon which their statements and conclusions rest. This task has not been easy. As Fredericks notes, parents and professionals alike have often made decisions regarding the form of services based upon personal past experiences, and their philosophies of the human condition. Once we have arrived at what we consider to be the current best model or practice, experts and parents alike fight hard to defend its "rightness" seeking funds for program support. Quite predictably numerous claims emerge regarding the efficacy of one model or approach over another. An example of this reality in terms of curricular approaches is described by Brinker.

Switzky and Haywood note that a common characteristic of the developed models, approaches and content is that they are rarely evaluated in a systematic manner. At best most developers undertake a one-shot study to evaluate a model, approach or some curricular content. Too often eloquence of argument is the standard for judgement and not an objectively valid body of knowledge generated through systematic research. Such a state of affairs can have catastrophic results. Consider, for example, the case of Edouard Sequin who, fired by the optimistic claims of Itard, advanced the "physiological method" and was, in large part, responsible for the establishment of an orientation toward educational habilitation of severely retarded individuals in state institutions in this country during the 19th century. Sequin promised that such an intensive educational orientation to treatment would have dramatic positive results but when the claims were not substantiated, a backlash developed which contributed to the predominant view of the early 20th century that institutional custodial care was the only appropriate treatment for the severely mentally retarded individual (Hewett & Forness, 1977). The result was that a pattern of care which emphasized modifiability through systematic intervention gave way to one of hopelessness and dehumanization. Is it not possible that we run similar risks in the decade of the 80s?

In particular, Switzky and Haywood emphasize two critical research deficiencies. First, the field simply lacks sufficient empirical findings in many areas critical to education and training of the severely mentally retarded person to arrive at objective decisions about the most effective approach. Second, the nature of the research conducted to date has been relatively narrow and there is a need to consider investigative approaches that may yield the type of information necessary to permit expanded interpretations of past and future findings. Alternatively, the White chapter underlines the need to enhance evaluation efforts with the severely mentally retarded, but from the perspective of more specific data collection techniques. Service delivery and research personnel must have a more adequate data base from which to draw conclusions and move forward. Without such a data base we continue not at our peril but the peril of the severely mentally retarded individual and his or her family.

SUMMARY

The purpose of this edited volume is to synthesize our most current information in critical areas that impact the severely mentally retarded population. It is not, nor is it intended to be, a methods or "how to" text. Contributors have reviewed the most current and pertinent literature in their area and then discussed issues they see as most salient. Each chapter concludes with a discussion of trends to be expected or areas that most need attention. The contributors have done an admirable job of highlighting the deficiencies in our current knowledge base. If, in the future, we fail to remedy these deficiencies through the application of our most adequate research techniques, then most likely we will witness a swing in the pendulum of support for current models and practice to antithetical positions. Guarantees for the future quality of service to the severely retarded will come only when efforts are firmly grounded on a foundation of objective knowledge. The goal of the editors will have been reached if, from the contributions to this volume, the reader gains an appreciation for the importance of well designed research to the development of effective practice.

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SECTION TWO/
THE BROAD CONTEXT

CHAPTER 2/

EDUCATIONAL POLICY AND SEVERE MENTAL RETARDATION[1]

MARGARET M. NOEL, PHILIP J. BURKE, AND CAROL H. VALDIVIESO

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Policy development
Policy implementation
Federal education policy
Federal legislation
Administration and monitoring
Administrative policies
Non-educational legislation
State educational policy
Policies prior to P.L. 94-142
    Trends in state policies
    Program administration
    Eligibility
    Service delivery
    Settings
    Funding mechanisms
    Personnel
LEA policy and implementation
Early implementation
Recent trends
Conclusions and future trends
Future trends
Reference Notes
References

To understand the current status of educational policy for severely mentally retarded (SMR) persons it is important to know that the basic structure of educational policy for all handicapped children is in transition. Prior to the early 1970s educational services for the severely handicapped as a class were, for the most part, permissive. That is, the services could be provided at public cost if the public sector chose to develop them. As a result of the major court actions, specifically Pennsylvania Association for Retarded Children (PARC) v. Commonwealth of Pennsylvania (1971) and Mills v. Board of Education of District of Columbia (1972), and the enactment of the Education for All Handicapped Children Act of 1975 (P.L. 94-142), the education of the severely mentally retarded became a right.

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[1] Attempts to identify legislation and policies specific to the SMR is difficult given that this population is incorporated either into the broader categories of severely handicapped or mental retardation. For example, the SMR are included in the definition of severely handicapped

However, the definition of services as well as questions regarding what constitutes "appropriate" education remain to be clarified within the structure of special education policy. This clarification is occurring through a complex interaction involving the state and federal courts, the Congress, state legislatures, and the Executive Branch of government. Throughout the process, the scope of some concepts has been expanded, such as the right to an extended year program, and others proscribed (e.g., Hendrick Hudson District Board of Education v. Rowley decision that appropriate education could not be defined in terms of "maximizing" the potential of the student). In addition to the court decisions, administrative proposals for regulatory changes have been made that would have substantially altered the implementation of P.L. 94-142. Thus, special education policy cannot be seen as an unalterable set of laws, or blueprints, but rather is best described in terms of a set of guidelines which are continually being changed by those who must put them into practice (Poister, 1978).

An examination of a specific policy requires a description of the blueprint and an examination of the implementation or use of those blueprints. In this chapter, the blueprints or legislative mandates will be discussed, and the current interpretations by states and local districts of those blueprints will be examined. However, before beginning a discussion of current educational policy pertaining to the SMR, it may be helpful for the reader to have some general notion of how policy is made and who participates in this process.

POLICY DEVELOPMENT

At the top of the system are the "policy developers" (Rostetter, Kowalski, & Hunter, 1983). These include the U.S. Congress and the state legislatures whose responsibilities are to define, through laws, the organization, struc-

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(SH) as specified in the program regulations of Special Education Programs (see Thompson, Wilcox, & York, 1980). For reporting purposes, however, states include the SMR in the category of Mentally Retarded (MR). Therefore, the legislative policies described herein pertain to either special education in general or the categories of severely handicapped and/or mentally retarded.

ture, and parameters of education. While legislative decision-making might be thought of as a rational process, it is usually an outgrowth of conflicting interests, values, uncertainties, and often incomplete information, resulting in laws whose language is vague, general, and even contradictory. The content of legislation is shaped by a political process of compromise and negotiation that reflects the political strengths of competing interest groups and their legislative representatives. Parent and advocacy organizations have played a major role in the shaping of special education policy.

The political process shapes not only the content of legislation but also the level of funding for a specific piece of federal legislation. Technically, the level of funding is determined by two processes: authorization and appropriation. The authorization process sets the ceiling or cap for possible funding while the appropriating process sets the exact amount (full, part, or none) of the authorized funds for any particular year.

While the legislative bodies have the power to author the laws, they obviously do not operate autonomously. First, all actions by these bodies must be consistent with existing federal, and in the case of state legislatures, state statutes. Second, as elected officials, lawmakers respond to the needs and dispositions of their constituencies. The legislative bodies are driven by organized interest groups such as parent and advocacy organizations. To the degree that there are common needs among these groups, laws can be relatively precise or at least straightforward. However, if there are competing priorities, laws may be drafted in language that is vague, general or contradictory.

Local school boards are also considered policy developers because they are empowered to develop local policy and procedures and have been given the authority to govern local school programs. However, in terms of special education for the SH they have served more as policy regulators. School boards have been particularly influential with respect to the implementation of the least restrictive environment mandate by setting policy regarding placement options and availability of services.

The courts must also be considered within the context of policy development. Their constitutional function is to "interpret" laws. These interpretations clarify policy and form the basis for policy decisions at lower levels, defining laws or providing more detail in the policy blueprint that states must implement. In this respect, courts have played a major role in defining special education policy.

Not to be overlooked is the powerful role of the Executive Branch in policy development and perhaps more importantly in its implementation. The support of the President is a critical determinant of successful federal policies, specifically in terms of setting budget priorities and supporting legislation. Presidents can set policy independent of the Congress through Executive Order, and a number of special commissions as well as major national initiatives in the area of the handicapped have resulted from a direct order of a President.

POLICY IMPLEMENTATION

Policy implementation is the process of putting into practice a policy blueprint. According to those researchers who have investigated that process (see Farrar, DeSanctis, & Cohen, 1980; Weick, 1976), policy development is evolutionary. They view policy in terms of what happens once a blueprint gets to the local service level with federal/state laws and policies serving only to define a set of priorities or "a domain for action" (Farrar et al., 1980).

The responsibility for the implementation of policy rests with administrators. The U.S. Department of Education is the administrative agency charged with carrying out federal education mandates. At the state and local levels, superintendents, directors of special education, and their line administrators have been delegated the authority to administer federal, state, and local policies.

Included within the authority designated to these bodies is the critical responsibility for developing the specific governing regulations that accompany legislation. This rulemaking power allows the agency to define the provisions of a law and set forth the guidelines for its implementation and administration. The importance of these regulations cannot be overemphasized as they become in fact *THE* policy or blueprint to be followed. The clarity and specificity of a set of regulations can determine the ease with which any law can move downward in the system, from the federal level to the states and local districts, and the consistency of the law's interpretation and implementation at the local level. In addition to rulemaking, administrative agencies have also been given adjudicatory power which allows them to elaborate on questions or concerns about policy and to resolve individual disputes. Through exercise of this authority, administrative agencies have evolved into policy developers in many instances (Edwards & Nordin, 1980).

Rules and regulations are not drafted in isolation from public opinion or need. Regulations are developed at each level of policy implementation, but the rulemaking process tends to be more structured and uniform at the federal level. Each administrative agency, from the State Education Agency (SEA) to the local public school, needs a set of guidelines that interpret policy and define specific actions. In the rulemaking process, considerable shaping, compacting, stretching, and shading of the original law occurs. At each level, this shaping is influenced by public opinion, political and economic climates, bureaucratic traditions or habits, as well as local custom and attitudes.

Ultimately, an educational policy must reach its intended recipient. For most educational policies, the final person involved in the implementation process is the teacher or other service delivery professional. Often overlooked in policy analyses, these individuals are considered to have significant influence in policy implementation (Hall, 1979). It is a long way from passage of legislation in the U.S. Congress to a classroom, and while administrative policies and procedures determine the system for delivering the services, the success or failure of the policy rests with the commitment and competence of the individual practitioners. As the structure of a policy is developed, the practitioner is critical in defining standards for services and setting precedents for quality. Recognition of the complex and interactive nature of what is called "policy" is important to understanding the remainder of the chapter.

FEDERAL EDUCATION POLICY

The emergence of the federal government in developing educational policy is relatively recent and is generally tied to the 1954 Supreme Court decision, Brown v. The Board of Education. In the early years, schools were established and administered by local communities with little governance by states. Schools were essentially autonomous units serving local needs and shaped by local attitudes. However strong the local commitment to public education, the concept of rights to education and equity did not prevail (Lynn, 1980). Care for handicapped individuals was provided within the home or community. As the country's population grew, the responsibility for the handicapped began to shift to the states which established institutions and similar centralized facilities as a means of removing the cost burdens from localities. In the late 1800s and early 1900s the humanitarian and reform movement in the treatment of the handicapped began to emerge in several private institutions. State and local officials saw this as a practical answer to an increasing problem. Placing the handicapped in institutions provided care and treatment, protected the handicapped as well as society and reduced the costs to the local communities. Thus, the early reform movement served as a basis for the public policy of providing for the handicapped in state-supported institutions (Lynn, 1980).

In the mid-1900s the first state compulsory education laws were enacted. These laws began to move education away from local perogative. While these laws did not include the handicapped, they did authorize the states to establish and maintain public education systems and strengthened the public policy base for education as a right and not a privilege (Howsam, 1981). Early in the 20th century, states began to enact legislation which permitted the operation of public schools or classrooms for the handicapped (Weintraub & Ballard, 1982). Despite such legislative authorization, the severely handicapped were routinely excluded from public schools. In fact, prior to 1973, many states had compulsory attendance laws that specified non-attendance of certain types of handicapped—most notably those classified as trainable or "feebleminded" (Zettel, 1982). In some states, nonretarded children with sensory and/or physical impairments were required to attend state-run schools, while moderately and severely retarded individuals were specifically excluded from the attendance laws (Oberman, 1980). This denial of access to education or training reflected, to a large extent, the general protectionist attitude of the public as well as lack of knowledge of the educability of this population.

Federal Legislation

The development of the federal policy base for special education is generally tied to the passage of two major pieces of legislation. In 1958, President Eisenhower signed into law P.L. 85-926 which provided funds to colleges and universities for training teachers for the mentally retarded. Also enacted in 1958 was the National Defense Education Act (NDEA). Title VII of that act authorized Educational Media Research which funded projects serving the mentally retarded. The NDEA provided the first major federal funding for education and gave the federal government power to regulate those funds, thus providing the basis for the federal role in education.

While those two acts represent major legislative landmarks, they were not the first federal initiatives in the area of the handicapped. In 1912, Congress established the Children's Bureau in the Department of Labor "to investigate and report" on issues related to child welfare, and in 1931, the U.S. Office of Education established a Section on Exceptional Children and Youth to document activities in the education of handicapped children. In 1950, two laws were passed authorizing the federal government to provide funds to local school districts serving children of federal employees. A "special education" clause in these statutes provided additional funds for handicapped children. The 1954 Cooperative Research in Education Act (P.L. 83-531) provided funds for research in the area of mental retardation.

The Kennedy administration began what Stedman (1981) has termed the "executive era" in special education. With strong advocacy from the executive level, a broad policy base was established, leading to the development of programs for research and direct service specifically designated for the handicapped. The Elementary and Secondary Education Act of 1965 (ESEA; P.L. 89-10) and its amendments (see Table 2.1) established federal aid to education as a national policy. In the early 1960s, amendments to the ESEA established a number of research and demonstration programs for the handicapped. Of particular note are the 1965 amendments (P.L. 89-313), the 1966 amendments (P.L. 89-750), and P.L. 91-230, the 1969 amendments.

Public Law 89-313 specifically authorized assistance to state-supported schools and institutions for education of the handicapped. Almost two-

Table 2.1 Educational Legislation

	Law	Major Provisions
1965	Elementary and Secondary Education Act (P.L. 89-10)	Represented major federal commitment in education ($1.33 billion). Provided grants to states for school districts serving low-income and "educationally disadvantaged" which included handicapped.
1965	Amendments to Title I of ESEA Federal Assistance to State Operated and Supported Schools for the Handicapped (P.L. 89-313)	Provided grants to state agencies directly responsible for providing free public education for handicapped children.
1966	Amendments to ESEA (P.L. 89-750)	Added a new Title VI which provided money to states to initiate, expand, and improve programs for educating the handicapped. Created the National Advisory Committee on Handicapped Children and BEH.
1967	Amendments to ESEA (P.L. 90-247)	Created Regional Resource Centers and Centers and Services for Deaf-Blind Children. Authorized grants and contracts for research, demonstration, and training of personnel in the area of deaf-blind. Authorized grants for recruitment of personnel, earmarked money under Title III (support for innovative programs) for handicapped, increased support to P.L. 89-313.
1968	Handicapped Children's Early Education Assistance Act (P.L. 90-538)	Provides grants and contracts for the development of experimental or innovative programs for preschool (birth to 8 yrs) handicapped.
1969	Amendments to ESEA (P.L. 91-230)	Created a number of new programs and consolidated several existing authorities into broader formats. Specific note: Title VI—consolidated several existing pieces of legislation. Created new program for funding model centers for the deaf/blind. This new consolidation entitled Education of the Handicapped Act.
1974	Amendments to ESEA (P.L. 93-380)	Contained significant legislative advances for handicapped. Expanded assistance to states to help them meet "right to education" mandates. Reduced restrictions on Title I money so that children served in public institutions could be moved to community facilities without loss of money. Special Note: Education for All Plans—states must submit detailed plans and timetable for providing full educational opportunities for all handicapped children. Also included are procedural safeguards, provisions for non-discriminatory testing, and mandates for integration of the handicapped into regular classes "whenever possible."

1975	Education of the Handicapped Act (EHA) (P.L. 94-142)	Amended Part B of 93-380 to sharply increase the federal commitment to ensure a free and appropriate education for all handicapped children. Included a new entitlement formula under which states receive funds based on number of handicapped children served. A percentage of this money must go directly to LEAs. States must guarantee full services for all handicapped between 3–21. Stipulates IEP and procedural safeguards. In order to receive funds, states must submit plans to U.S. Department of Education describing procedures and programs. LEAs must submit plans to state. SEA is responsible for insuring that provisions are carried out.
1977	Amendments to EHA (P.L. 95-49)	Extended for 5 years a number of discretionary grant programs. Part B was not altered.
1978	Amendments to EHA (P.L. 95-561)	Extended ESEA Title I for handicapped children and P.L. 89-313 and specified that programs eligible for funds under the latter must be consistent with the provision of Part B, P.L. 94-142.
1983	Amendments to EHA (P.L. 98-199)	Extended and revised 10 discretionary programs. Established new secondary and transitional program. Provided funds for evaluation of effectiveness of services. Provided financial incentives for expanding services to birth.

SELECTED RELATED LEGISLATION

1944	Public Health Services Act (PHSA)	Created the National Institutes of Health
1962	Amendments to PHSA (P.L. 87-838)	Established the National Institute of Child Health and Human Development (NICHD) which funds research and training in human growth and development. One branch focuses on research on prevention of mental retardation.
1963	Mental Retardation Facilities and Community Mental Health Centers Construction Act (P.L. 88-164)	Provided funds for construction of University Affiliated Facilities (UAFs) which are interdisciplinary facilities conducting research and training in the area of mental retardation. Also funded research and demonstration programs in the education of mentally retarded. Amended P.L. 85-926 (NDEA) to provide training programs for special education personnel.
1965	Amendments (P.L. 89-105)	Extended and expanded existing grant programs in the area of personnel training and research and demonstration programs.
1967	Amendments (P.L. 90-170)	Extended and expanded UAFs. Established a new program for community mental retardation facilities. Provided research, demonstration, and training programs for physical education and recreation for the handicapped.
1970	Developmental Disabilities and Facilities Construction Amendments (P.L. 91-517)	Significantly expanded P.L. 88-164. States were given broad responsibility for planning and implementing comprehensive programs for the severely disabled. Designed to ensure that severe or multiply disabled were given priority. Provided grants to states to assist in developing a range of services for the "lifetime needs" of the DD. Also set standards for institutions and similar public agencies.

Table 2.1 (Continued)

	Law	Major Provisions
1975	Developmentally Disabled Assistance and Bill of Rights (P.L. 94-103)	A new law which contained the basic provisions of P.L. 91-517.
1920	Smith-Fess Act Vocational Rehabilitation Act	Original legislation focused on vocational rehabilitation. Designed for WWI veterans. It is one of the nation's oldest and most effective grant-in-aid programs.
	Amended in 1943, 1954, 1955	Scope expanded to include disabled and handicapped.
1965	Amendments to VRA (P.L. 89-333)	Improved and expanded existing legislation. Provided grants to states to develop new and innovative techniques and programs for the severely disabled.
	Amended in 1967, 1968	
1973	Amendments to VRA (P.L. 93-112) The Rehabilitation Act	The Act was recodified and emphasized expanding services to the most severely disabled. Established the Rehabilitation Services Agency (RSA) within HEW. Contains Section 504—The Handicapped Bill of Rights.
	Amended in 1974	
1978	Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendment (P.L. 95-602)	Consolidated P.L. 93-112 and the DD Act (P.L. 94-103). Authorized a new program of independent living services. Created the National Institute of Handicapped Research to stimulate and coordinate research into the special needs of the handicapped; created the National Council on the Handicapped to review and advise on all policy and programs for the handicapped conducted by the federal government; established Office of Handicapped Individuals as a national information clearinghouse; established the Architectural and Transportation Compliance Board.
1984	Amendments (P.L. 98-221)	Designated the National Council on the Handicapped as an independent agency and expanded its role in evaluation of all handicapped programs. Client Assistance Projects became mandatory and set standards for evaluation of Independent Living Centers.
1935	Social Security Act (SSA) (P.L. 74-271)	Provided support for child welfare and Crippled Children's Services.
1956	SSA Amendments (P.L. 84-880)	Title XIV is added which provides benefits to permanently and totally disabled adult dependents of eligible retired or deceased workers.

1963	SSA Amendments Maternal and Child Health and Mental Retardation Planning Amendments (P.L. 88-156)	Designed to carry out the recommendations of President's Panel on MR. Provided grants to states to expand programs for crippled and other handicapped children and to assist states in developing comprehensive state and community services for the handicapped.
	Amended in 1964	
1965	SSA Amendments (P.L. 89-97)	Medicaid programs established for low-income and disabled persons. Authorized funds for training personnel to care for the mentally retarded and multiply handicapped. Provided benefits for adult institutionalized handicapped.
1967	SSA Amendments (P.L. 90-248)	Amended Title XIX (Medical Assistance) to require early identification and treatment of handicapped children.
	Amended in 1969, 1971	
1972	SSA Amendments (P.L. 92-603)	Title XVI—Supplemental Security Income (SSI) added. Provides direct income support to the disabled. Major source of income for the severely handicapped.
	Amended in 1973	
1974	Social Services Amendments (P.L. 93-647)	New Title XX. Authorizes grants to states to develop and expand programs that foster independent living and deinstitutionalization.
	SSA Amended in 1977, 1978, 1983	

thirds of these funds were directed to the mentally retarded in state institutions. Public Law 89-750 served as the basis for federal involvement in special education. In addition to providing grants to states to stimulate program development and funds for research and personnel training, it also mandated the creation of the Bureau of Education for the Handicapped (BEH) within the Office of Education. This created a central administrative agency for federal special education programs. With the creation of the Department of Education, BEH became the Office of Special Education (OSE); in 1982 it became Special Education Programs (SEP) and is now known as the Office of Special Education Programs (OSEP).

Public Law 91-230 (the 1969 amendments) was particularly comprehensive and provided funding for the creation of a number of new programs as well as funding to states to initiate or expand services to the handicapped from preschool through the secondary level. Title VI of this law consolidated a variety of separate pieces of legislation related to the handicapped. This new part of P.L. 91-230 became the first Education of the Handicapped Act.

Administration and Monitoring

As each program was added, a section or part of BEH was designated to administer and monitor the individual program, including developing specific regulations to govern program operations as well as establishing procedures for disbursing the funds. The latter could include establishing priorities for funding (such as handicapping condition or program type) as well as the percentages of available dollars to be allocated to a given priority. Through the development of program regulations and the award of grants and contracts, the agency assumed a major policymaking posture within special education.

While the federal government was beginning to respond to the needs of the handicapped, states were moving ahead with their own legislation for education of the handicapped. The basic issue at the state and local level was access to education, and parents began to pressure state legislatures to provide funds for programs. Through political pressure and litigation, parents, professionals, and other citizen advocates were forcing major change in state education policy. By 1972, close to 70 percent of the states had enacted legislation mandating education for the handicapped (Weintraub & Ballard, 1982).

The pressures for change were acute, and the momentum for change in the educational system was being fueled by parents. Still many children were being denied a public education. Severely handicapped persons were, in general, excluded from education even under new state statutes. However, a major drive to secure education for this population was beginning, stimulated to a large extent by the behavioral research that was demonstrating the benefits of educational programming (Stainback & Stainback, 1980).

Pressure from parents and citizen advocate groups resulted in several major court decisions. Elements of those decisions as well as features of selected state legislation became incorporated into the Educational Amendments of 1974 (P.L. 93-380). This legislation contained many elements of the later P.L. 94-142; however, it did not mandate that these elements be in place. Public Law 98-380 did require that states submit a detailed plan and timetable for providing public education opportunities for the handicapped.

As more and more states felt the pressure to provide special education to a wider range of students and enacted legislation to provide funds for these programs, the budgetary problems mounted. Governors and Chief State School Officers appealed to the Congress for assistance (Lynn, 1981). Parents and advocacy groups were also appealing to Congress for a strong federal mandate that would reduce inequities among states and put "teeth" into state legislation. The result was that in November, 1975, the Education for All Handicapped Children Act (P.L. 94-142) was enacted. The law, widely recognized as a major piece of social legislation, attempted to address a number of diverse and at times conflicting, issues. It represented the interests of parents, advocates, and the professional community as well as the concerns or needs of state and local school officials. The original intent or goal of the law was essentially pragmatic . . . to provide financial assistance to states (Howsam, 1981; Lynn, 1980). The first priority was to provide services to the unserved, largely the SH. The law was specific; however, Congress was reluctant to interfere with state and local discretion, particularly in defining the precise nature of the services to be provided. The implementing regulations, published in 1977, did contain further definition and clarification of the law, but did not specify the precise way in which children were to be served (see Lasky this Volume). The attempts to provide a strong enforceable law while balancing state's rights resulted in regulations that allowed room for interpretation and created problems in state and local implementation.

The immediate and major debate in Congress at the time of the passage of P.L. 94-142 was over the authorization levels or dollars to be made available to states for implementing the law; the specific services to be delivered were addressed. Congress was aware that the final appropriation level would never be sufficient to meet the potential of the law, and while the parents and advocates viewed the law as a major philosophical change and the beginning of a revolution, school officials were ambivalent and wary. The law, however, did provide a powerful lever for change, in that it forced consideration of the handicapped (Sarason & Doris, 1979).

Administrative Policies

As early as 1973, BEH began a major initiative in the area of SH (Thompson et al., 1980). A Task Force was convened to study the problem and make recommendations for future BEH activities. The Task Force estimated that almost one million SH were totally excluded from the educational system and some 300,000 more were not being served adequately. The principal problems were seen as a lack of state legislation mandating service to this group, a lack of trained teachers, lack of program models, curricula and materials, and a general lack of concern for these students.

The Task Force developed a definition of SH to assist BEH in focusing its programs and funding priorities. It also developed the first of a series of Request for Proposals (RFPs) resulting in the award of contracts to local or state education agencies and universities to develop demonstration service programs. The first of these RFPs, issued in 1974, funded programs in telecommunications and comprehensive service delivery. During this same year, the U.S. Commissioner of Education issued a memorandum to the Chief State School Officer in each state indicating that SH had been given priority status within the Office of Education and also assigned BEH the responsibility for monitoring national progress in this area. In response, BEH created the Special Services Branch within its organization, giving official status to programs for SH. Further RFPs were issued, providing funding for general program models for various types of SH students. In 1978, the RFPs called for development of innovative models or approaches to teaching SH while the most recent RFPs have focused on development of state-wide systems change models designed to incorporate new practices into local school programs. Through both the funding and administration of these programs, BEH was a significant force in the shaping of state and local policy.

Non-educational Legislation

To this point, the focus has been on the federal educational legislation and policies. Federal policy initiatives for the handicapped have not, however, been solely within the area of education. At least three other legislative "packages" have influenced educational services for SH individuals (see Table 2.1). One of the most significant was the Smith-Fess Act of 1920 which became the Vocational Rehabilitation Act. The 1973 amendments to this Act (P.L. 93-112) included Section 504 . . . the major civil rights mandate for the handicapped (LaVor & Duncan, 1974).

The 1978 amendments of this act established several administrative offices with important regulatory functions in the area of rehabilitation and handicapped services. In 1979, with the reorganization following the establishment of the Department of Education, these offices were included, with BEH redesignated the Office of Special Education, within the Office of Special Education and Rehabilitation Services (OSERS). The Office of Civil Rights, established as a separate entity within the Department of Education, was charged with monitoring compliance to Section 504 in programs aided by the Department.

Another major piece of legislation that has provided services to SH persons is the Social Security Act of 1935. Original provisions in the law included support for child welfare and crippled children's programs. In 1957 the disability provisions and public assistance programs were added, and SH individuals, while never specifically identified, became eligible for assistance under aid to the permanently and totally disabled (Title XIV). By the early 1970's, this act was providing the greatest amount of federal monies to SH children and adults (President's Committee on Mental Retardation, 1977). Subsequent amendments to this law strengthened the commitment to the severely handicapped and through the Supplemental Security Income (SSI) provisions promoted the concept of deinstitutionalization. These SSI payments have provided for participation of the SH in community programs, including group homes and vocational programs.

Several other selected pieces of legislation are noted in Table 2.1. These do not represent all legislation relating to the handicapped in general nor to the severely handicapped. However, the laws noted in the table are among those providing more substantial benefits to the SH population. The amount of legislation pertaining directly to the handicapped is extensive. For example, there are over 42 separate federal programs targeted for the handicapped with an annual budget in excess of $36 billion. In addition there are more than a hundred other programs that provide services or support to this population ("Reagan announces," 1983). In addition to education, the programs address diverse areas such as housing, health, employment, and transportation. While many do not provide for direct funding of programs, they do represent the extent of the federal involvement in the area of the handicapped.

STATE EDUCATION POLICY

If policy development followed a rational, top down process, the educational policies of individual states would be a mirror image of federal law and policies. However, while federal policy can direct attention to a problem and provide ways for policy to be applied, state and local procedures actually represent a compromise with federal policy, the effectiveness of which depend heavily on two factors . . . availability of resources and strong local support for the policies (Elmore, 1980).

The roles of State Education Agencies have shifted dramatically over the past 20 years. Initially, states were the only policy makers in special education. States assumed a "benefactor role" (Weintraub & Higgins, 1982) and viewed special education as a charitable act. States did not mandate services for the handicapped and provided little if any financial support to local districts that chose to provide services. Policy differences among states were due to the degree of commitment to the handicapped and the capability of the state to finance services, as well as the degree of control a state exerted over its local districts. In general, however, the SEAs' roles have included two functions: regulating (e.g., teacher certification, setting standards for class size) and; technical assistance (e.g., curriculum development, in-service training). Most states have traditionally monitored more than they have provided assistance in program delivery (McDonnell & McLaughlin, 1981).

Policies Prior to P.L. 94-142

In 1949, the U.S. Office of Education published a review of state legislation pertaining to special education (see Martens, Ellis, Graham, Lipton, Myer, Stanton, Stoddard, & Wagner, 1949). At the time of the report, many states had statutes that allowed special education to be provided by local districts *and* had provisions for contributing to the costs of those services. However, only two states mandated special education services. Only 19 states specified mentally retarded, mentally handicapped or "subnormal" as eligible for services. Generally, all state statutes established a range of allowable services and included transportation, special appliances, therapeutic care, lunch, and training of teachers. However, there was much variability among states.

As Congress began to create new education programs in the 1960s, states also began to assume a direct policymaking role in special education. Under pressure from parent groups and in some cases judicial mandates, SEAs began to develop explicit policies for special education, including defining who would be eligible and specifying how children were to be served. Unlike other federal programs for special populations, such as Title I or compensatory education, states led the federal government in developing special education policies (Weintraub & Higgins, 1982). In 1972, 70 percent of the states had enacted legislation mandating education for all handicapped children. Some states, such as Massachusetts and Tennessee, enacted extremely comprehensive legislation that included many of the provisions that were to later be incorporated into P.L. 94-142. However, much diversity remained, and existing federal special education legislation was not providing strong mandates or adequate funding. In fact, only about 15 percent of the money required to finance special education programs was coming from all federal sources (Lynn, 1981).

With the passage of P.L. 94-142 came a major change in the SEAs' role. The law gave the SEAs specific responsibility for ensuring that local districts and other public agencies providing education to handicapped children comply with all provisions. The regulations specified 21 areas in which states were required to develop policies or procedures. The regulations also required that states both monitor their districts' programs and provide technical assistance and training to their districts. In addition, states were required to report annually to BEH on numbers of children served, their placements, and types of services provided as well as personnel employed.

The law was directive in defining states' responsibilities, and some policies have become almost uniform across states. However, despite the strong mandates, special education policies do differ from state to state in some significant ways. The differences are primarily the result of two factors. First, for all the precision of P.L. 94-142, it emphasized procedures and not service delivery (Howsam, 1981). While the goal of the act was to provide appropriate education in the least restrictive environment (LR[illegible] the definition of "appropriate" was left to states and locales. Furthermore, LRE was more a statement of principle or philosophy and not specifically defined to mean education in regular public school settings (Joe & Farrow, 1981; Rostetter et al., 1983).

A second major factor impeding implementation of the law is that the federal contribution to special education has provided only a small percentage of the total costs of these services. During the 1979–80 school year, states provided an estimated $3.4 billion or an average of $858 per pupil; the federal contribution under P.L. 94-142 was $804 million or $218 per pupil served. While these estimates of states' costs are considered low, their contributions to local programs ranged from 98 percent to 17 percent with the remaining money coming from local sources (Moore, Walker, & Holland, 1982). The bulk of the state funds have come from the general education fund with little contribution from other state agencies such as vocational rehabilitation or departments of mental health and retardation. In fact, states have reported that some agencies that once met some major program needs now leave all services to the educational system. Thus, differences in state educational policies largely reflect the general wealth of an individual state, the strength of its commitment to the handicapped, and its available resources.

Trends in State Policies

Individual state policy generally is focused in five areas: administering programs, determining eligibility, establishing range of services, determining costs, developing funding formulas, and developing policies for certification and training of personnel.

Program Administration Under P.L. 94-142, states have had to develop specific policies for both monitoring and providing technical assistance. In the early years of the law, states had few staff assigned to these tasks and provided little of either (U.S. General Accounting Office, 1981). However, recent data (U.S. Department of Education, 1984; McDonnell & McLaughlin, 1982), indicate a general improvement in state monitoring procedures. In addition, special education departments have been elevated within the hierarchies of the SEAs and have increased supervisory and administrative staff.

Eligibility All states have established categories for reporting child count data to SEP. However, some states classify children one way for reporting and another way for providing service; a number of states have moved toward defining children in terms of severity of handicap. In a 1979 survey of states conducted by the National Association of State Directors of Special Education (NASDSE) (1979), 23 states plus the District of Columbia, and two territories reported having established a specific category for Severely/Profoundly Handicapped. The purpose of broadening the categories was to allocate funds to match service delivery needs. Twenty-one of these states included the SMR. Other states classify these children as trainable mentally retarded (TMR). Included in the eligibility policies are the age ranges to be served. Public Law 94-142 specifies the age ranges of 3–21. However, 3–5 and 18–21 are mandated only if it is consistent with state law. Six states mandated services from birth (McGuire, 1982). Of the remaining states, all but four had permissive legislation allowing services for the birth to 3 and/or post 21 population.

Service Delivery Some of the greatest variability among states exists in the services that are provided to SMR individuals. Much of the control over the organization and delivery of specific services rests with the individual LEAs. However, decisions regarding what special education and related services are required by P.L. 94-142 are major state policy issues. In addition, defining the types of placement options is a state responsibility.

Policies related to assessment and class sizes also vary across states, with the trend toward requiring a larger assessment team for the more severely handicapped. Other major policy issues concern the length of school year and related services. A number of states have tried to limit the number of days of education it must provide to handicapped students. Some states have included these limits in statutes; others have issued policy directives prohibiting extensions of the school year. In addition, some states have established policies that set specific standards for determining when a child should be provided year around schooling (Moore, et al., 1982).

In determining what related services can be provided, states have had much latitude. The term "related services" was broadly defined in P.L. 94-142 with the exception of medical services for purposes other than diagnosis and evaluation, which were excluded. As a result, some states have classified a number of services, such as physical therapy, occupational therapy, and catheritization as medical service and, thus, not required to be provided (Moore et al., 1982). The Supreme Court has recently ruled (Irving Independent School District v. Tatro, 468 U.S., 1984) that school systems must provide catheritization as a related service to help handicapped students to benefit from education.

Settings One of the most pressing policy issues in the area of placement of SMR students is the degree to which these students are integrated into regular education settings. The data on the placements of severely handicapped differ depending on the source. In the 1979 NASDSE survey, states reported that 50 percent of SH students were being served in public school settings, 16 percent in private settings, and 34 percent in state-operated facilities. Data from the National Survey of Individual Education Programs (Pyecha, 1980) revealed that during the 1979 school year, only 13 percent of the handicapped children being served by public schools were severely handicapped. Furthermore, 86 percent of the mentally retarded in public schools were classified as mild or educable. The Sixth Annual Report to Congress (1984), indicated that fewer than 7 percent of all handicapped children were receiving education outside of the regular education building. However, 25 percent of the children were served in self-contained classes. Determining the placement of SMR is complicated by the fact that states report totals for MR, and no distinction is made between mild/moderate and severe. However, the data indicate 47 percent are served in separate classes, while 39 percent are served in special schools and about 1 percent in "other" settings. However, 29–95 percent of the children being served under P.L. 89-313, where dollars typically go to special schools or residential facilities, are identified as MR (Rostetter, personal communication, November, 1982).

Funding Mechanisms The topic of school finance is complex and cannot be fully addressed in this chapter. However, it should be noted that the way in which states fund special education programs influences other policies such as services, placement, and eligibility. One of the major problems in special education finance has been determining the per pupil costs of special education services. Recent cost estimates for educating a TMR child is 3.34 times what it costs to educate a non-handicapped child (Winslow & Peterson, 1981). If a state chooses to provide "excess costs" based on a child's handicap, it would provide some portion of these additional costs for every TMR child a district serves, regardless of the actual services being provided. Some states provide a fixed amount for every handicapped child, regardless of handicap, while others provide allowances based on numbers of teachers or classes. Each of these models can have a different influence on the quality of services provided.

Personnel Perhaps the most critical variable in the education of the SMR is the quality of the personnel who provide the education. State policies usually encompass two areas, certification and in-service training. With respect to certification, states differ markedly in their requirements for licensure. Of the states responding to the 1979 NASDSE survey, only 11 had specific certification requirements for teachers of the severely handicapped. However, according to a recent national survey of personnel needs (Smith-Davis, Burke, & Noel, 1984), 27 states/territories have categorical certification which means that personnel are licensed to teach a specific handicap, such as mental retardation. Among the remaining 26 jurisdictions which have non-categorical or cross-categorical certification, 16 require special endorsements for teaching the severely handicapped.

In the area of in-service, states have an explicit responsibility, under P.L. 94-142, to provide training to regular and special educators to ensure quality instruction for students. States have viewed this as a critical need area, particularly in the area of the SH where teacher shortages have been great. To date, however, states have tended to place this training function below that of regulating compliance.

Generally, states have tended to follow closely the policies articulated by the federal government and, thus, have increased their authority over local districts. In fact, the strong federal mandates have resulted in some erosion of the historic local control of education and creation of more uniformity among state policies.

LEA POLICY AND IMPLEMENTATION

The purpose of the federal mandates as well as the state policies has been to improve practices at the local district level. The problems encountered during implementation of a comprehensive set of policies such as those initiated by P.L. 94-142 have been numerous, and a number of studies of local implementation have been conducted (e.g., General Accounting Office, 1981; Hargrove, Graham, Ward, Abernethy, Cunningham, & Vaughn, 1981; Pyecha, 1980).

Early Implementation

An initial major problem faced by local districts was the lack of specific guidelines and precise requirements for meeting the law. Districts were confronted with a strict timeline for providing a comprehensive array of services and at the same time had to develop a range of new local policies and procedures for each requirement. As a result, districts began to develop unofficial policies for controlling or managing the new workload. An example is in the area of parent involvement. Because the nature of this involvement was never fully defined, districts responded by developing a variety of ad hoc procedures, such as seeking blanket approval from parents or simply requiring parents to sign an IEP after it was developed. In addition to the lack of guidelines, there was a lack of technical assistance from states in designing programs or procedures. Largely because of the numerous procedural requirements, states have focused efforts on monitoring and compliance.

A second major problem and one that continues today was insufficient funding for programs. Despite federal and state contributions, local districts ultimately have had to furnish the majority of funds for their programs. Without adequate money, districts could not increase their administrative and instructional staffs to accommodate new demands for service. In addition to lack of funds was the lack of qualified personnel, including specialists such as occupational and physical therapists. Faced with the demand for immediate service, districts responded by establishing unwritten policies that rationed services limiting the amount of therapy a child could receive, regardless of individual need.

Districts responded to the personnel shortage by hiring, on provisional or emergency certificates, specialists in training or teachers who lacked specialized training in the area of the severely handicapped. While all of these procedures allowed districts to meet the basic legal requirements, the lack of trained personnel significantly restricted the quality of the services that were provided.

Recent Trends

Recent studies have shown a gradual improvement in LEAs' ability to fully implement the law (see Sixth Annual Report to Congress, 1984). These studies indicate an overall improvement in procedural compliance. LEAs also report more positive attitudes toward IEPs and greater efficiency in the procedures for developing them. In fact, a large number of the districts have indicated that they have instituted requirements for their IEPs that go beyond those specified in the law. In addition, the extent of parental involvement in the development process is reported to have increased. However, this is attributed to the increase in parent awareness and understanding of their rights and of what constitutes appropriate education for their child.

These conclusions are supported by data from a longitudinal study conducted by Stanford Research Institute (SRI, 1982) on local implementation of P.L. 94-142. This study noted that emphasis during early years of the law had been on developing and routinizing procedures, while recent efforts have been focused on filling gaps in services, primarily at the secondary level and in vocational education. Further, an increase in the number of classes for SH and TMR students within regular public school buildings, particularly at the secondary level has occurred.

Collectively, federal and state policies have improved the array of services available. Where a few years ago the issue was availability of service within the public school, it is now focused on the integration of those services and the quality and range of services offered. Despite the lack of full funding, the federal monies have increased the concentrations of money available to the handicapped. In general, districts are now concerned less about procedures and more about services. While much remains to be accomplished toward full realization of the promise of P.L. 94-142, public education for the severely handicapped is now a reality and not a promise.

CONCLUSIONS AND FUTURE TRENDS

Significant changes in both economic conditions and political climate have occurred over the last few years. These changes are affecting the policies which govern special education. Many states are faced with serious budget deficits, and local school districts are finding it difficult to get voters to approve new school levies. Such funding limitations are forcing schools to critically examine the costs of their existing programs and are curtailing any expansion of services.

The political climate which supported growth of strong federal programs for the handicapped changed drastically with the Reagan Administration. Essentially this administration believes that the federal government has taken on responsibilities in education, as well as health and social services, that are not its constitutional responsibilities. This administration also believes that states and locales are capable of providing these necessary services more efficiently and economically than the federal government. Furthermore, while states may need additional revenues to meet their responsibilities, the funds should come with a minimum of regulation and control.

One of the first acts of the administration was to propose to Congress the consolidation of a number of categorical programs (e.g., programs focused on specific populations with specific purposes) into large block grants that would provide money directly to the states to support a broad range of activities but which would have few regulations or require little accountability on the part of states. The Education of the Handicapped Act was originally included in the block grant legislation. Due to the active efforts of parents, professionals, and other advocates, EHA was removed from the block grant and remains a separate piece of legislation with its own funds and regulations. Other programs such as the Vocational Rehabilitation Act and the Developmental Disabilities Act also remain separate and categorical; however, a number of health programs including Maternal and Child Health, Crippled Children's Services, and Rehabilitation Services for Disabled Children under SSI were consolidated into one block program. Under block grants, states may use the funds for any of the authorized programs, but are not required to maintain prior levels of effort. The fact that other programs for the handicapped did not lose their national identity and funding base is an indication of the public support base for these programs.

The rate of growth of state special education funds has surpassed that of other educational programs (McGuire, 1982). This increase is likely to continue, although, at a somewhat slower pace, because of two interrelated factors: the strong legal mandates and popular support for these programs. Without strong legal mandates, it is almost assured that less money would be provided for special education, and without strong public support, it is likely that there would be a repeal or weakening of existing federal and state legislation.

Future Trends

To maintain the critical support of the taxpayer, special education's most urgent need is accountability to the public, to show that its programs and practices work and produce performance changes (Joe & Farrow, 1981; Macchiarola, 1981; Stedman, 1981). A trend that needs to be continued is the integration of special education into the mainstream of education. No longer can the education of the handicapped afford to be seen as a small specialized area of education. Special education needs to strengthen its interdisciplinary relations with medicine, rehabilitation, and general education and consolidate its services into a broader system. By reducing this separation, services can be expanded and costs will be reduced. The emphasis on developing interagency agreements is a response to this reorganization. Also required is a change in the way special education teachers are trained. Teachers and support personnel need knowledge of many systems and they need training and experience in how their discipline fits into these systems, including cross-disciplinary programming and consultation with other specialists (Howsam, 1981; Joe & Farrow, 1981; Stedman, 1981).

Related to this integration of services is the trend toward developing more efficient delivery systems in general. The focus for the immediate future will be on refining the nature of services, particularly those classified as related services, and on finding more economical and effective ways to deliver them.

In general, the trend for policy in the 1980's will likely focus on efficacy and finance, specifically to ensure that the goals of a free and appropriate education can be maintained with less fiscal impact on all levels of government.

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CHAPTER 3/
JUDICIAL ADDRESS OF EDUCATION FOR STUDENTS WITH SEVERE MENTAL RETARDATION: FROM ACCESS TO SCHOOLS TO STATE-OF-THE-ART

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Early Right-to-Education Cases
PL94-142 and Judicial Interpretation
State-of-the-Art Requirement
Summary
References

As late as the early 1970s severely handicapped children were shut out of the public schools. Their exclusion was not without reason. Public school officials routinely explained to parents that their children were excluded because:

- We [the public schools] do not have classes for severely handicapped children.
- We do not accept children who have not reached a mental age of five years.
- We do not accept retarded children who are nonambulatory.
- We do not accept handicapped children who are not toilet trained.
- We do not accept handicapped children who have behavior problems.
- We do not accept children with multiple handicaps.

Those few parents who managed to enroll their severely handicapped child in school could expect after the brief time to hear, "We are going to excuse your child because she can *no longer benefit* from our program" (Lippman & Goldberg, 1973).

Federal Court Action, *Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania* (*PARC*) filed January 1971, marked the beginning of the end of school exclusion for severely handicapped children. The *PARC* case also initiated a series of judicial decisions and legislative acts which have created and shaped the right to education for severely handicapped children. It also marks the beginning of continuing judicial oversight of public education programs for handicapped students.

Federal court right-to-education decisions of the 1970s and the subsequent interaction of legislative and administrative processes has created an intricate legal structure to assure the education of severely handicapped students in public schools. A decade of legal developments has completely reversed the power relationship between local school officials and parents and has permanently changed the rules and standards governing public school programs for severely handicapped children.

The changes sparked by legal action of the 70s are revolutionary. The extent and magnitude of the changes are demonstrated by the reversal of the burdens and the imposition of enforceable responsibilities to provide education from which all children can benefit. In 1972 if local school officials asserted that a handicapped child could not benefit from the available public school program, the child and his parents were in serious trouble. Today, if the parents assert that their child is not benefitting from instruction, the school is in serious trouble.

In 1972 the *PARC* Court struck down state laws that previously legitimatized school exclusion of handicapped children not able to benefit from schooling. In 1982 the U.S. Supreme Court in the *Rowley* case interpreted federal law to require local school districts to provide educational and related services, "as are necessary to permit the child 'to benefit' from instruction" (*Hendrick Hudson Central School District Board of Education v. Rowley*).

The path from *PARC* to *Rowley* has not followed a straight line. However, recent Supreme Court interpretations of federal law governing educational rights of handicapped students make it clear that school districts have significant procedural and substantive legal responsibilities to handicapped children. These interpretations will require continuing judicial involvement as to the adequacy of educational programs for severely handicapped children. In order to gain some understanding of the current state of the law and the legal responsibilities of state and local school officials, this chapter briefly reviews the legal foundation and impact of the early right-to-education cases, the congressional codification of the right-to-education principles in P.L. 94-142 and judicial interpretation of the federal mandates.

EARLY RIGHT-TO-EDUCATION CASES

Approving the decree in the *PARC* case, the three judge federal court found:

> [A]ll mentally retarded persons are capable of benefitting from a program of education and training; that the greatest number of retarded persons, given such education and training, are capable of achieving self-sufficiency and the remaining few, with such education and training are capable of achieving some degree of self care.

In 1972, the *PARC* consent decree established in law the principle that a state could not deny any mentally retarded child access to a free public education. However, the original *PARC* decree established more than the principle of non-exclusion. As Supreme Court Justice Rehnquist recently acknowledged, the *PARC* decree incorporated the substantive standard that each child receive "access to a free public program of education and training appropriate to his learning capacities," and that the state is required to take action in the event that, "the needs of the mentally retarded child are not being served." See, *Board of Education v. Rowley*, 102 S.Ct. 3034, 3044, at note 15, quoting *PARC I*, 334 F. Supp. 1258 and 1266. The *PARC* decree also set forth the integration principle stating that: "Among the alternative programs of education and training required . . . to be available, placement in a regular public school class is preferable to placement in a special public school class and placement in a special public school class is preferable to placement in any other type of program of education and training." The chief programs of the "other type" were in state institutions. In Pennsylvania at the time of the *PARC* decree, 4,154 school-age retarded children, nearly all severely handicapped, were in institutions. Over 3,000 received no program of education or training (*PARC* 334 F. Supp. at 125).

Although the *PARC* case was widely noted, and followed throughout the country for its success in establishing access to the schools for the thousands of severely handicapped students previously excluded, the decree itself and the initial implementation of the decree focused on the necessary conditions of schooling for severely retarded students after they were admitted to the schools. The *PARC* decree required Pennsylvania to undertake a planning process to establish and implement the substantive standards and content for appropriate educational programs. Paragraph 50, designated by Judge Masterson of the three judge *PARC* Court as the most important part of the decree, required a state plan in order to:

> Specify the range of programs of education and training, their kind and number, *necessary to provide an appropriate program of education and training to all mentally retarded children*, where they shall be conducted, arrangements for their financing, and, if additional teachers are found to be necessary, the plan shall specify recruitment, hiring, and training arrangements. (emphasis supplied)

The decree also provided for the specification of hours of instruction, pupil-teacher ratios, curriculum facilities and teacher qualifications.

The state planning process resulted in a 1973 Commonwealth Plan for Training of Mentally Retarded Children (COMPET). The curriculum and standards developed were borrowed from existing programs and did not adequately address the educational needs of the severely handicapped student. A review of COMPET commissioned by the court appointed Masters found that the curriculum:

> does not provide for the broad range of retarded children. Generally the modules do not extend downward to include the very low functioning students.

The Court Masters were particularly concerned about the inadequacy of the curriculum for the multi-handicapped child, the autistic child, and those children classified as having maladaptive behavior.

The PARC decree mandated the developments of substantive standards, curriculum, and teacher competencies to govern the delivery of educational programs for all mentally retarded children including those who were severely and profoundly handicapped. However, the state and local school districts gave little attention to the children. The accomplishments of the court were measured primarily by the numbers of handicapped children given access to the public schools.

PL94-142 AND JUDICIAL INTERPRETATION

The court action in the early 70s was followed in 1974 and 1975 by Congressional guarantee of free appropriate public education for all handicapped children. The predominant issue became one of quality of education. Access to the schools did not necessarily mean that relevant education was occurring in classes for severely handicapped students. With the exception of a number of centers associated with university-based research and personnel preparation programs, severely handicapped children were consigned to segregated facilities with inappropriately prepared teachers, without appropriate curricula and without professional staff skilled in the delivery of related services. The state of education for severely handicapped students was explicitly recognized by the Congressional directive in P.L. 94-142 which stated that children "with the most severe handicaps who are receiving an inadequate education", 20 U.S.C. §1412(3), be given priority.

Once severely handicapped students were identified and placed in public school programs, parents soon began to question whether the instruction provided to their children was of benefit. Those questions when posed in judicial forums, forced state and local school officials to address the purposes and necessary conditions for quality education for severely handicapped children. Education for severely handicapped students necessarily broadened the concept of formal public education. As one court made clear, "Where basic self-help and social skills such as toilet training, dressing, feeding and communications are lacking, formal education begins at that point" (*Battles v. Commonwealth of Pennsylvania*). The unique needs and learning characteristics of severely handicapped students necessitated changes in longstanding rules and practices. For example, the rationale for a 180 day school year and a six hour school day could not withstand judicial scrutiny when applied to severely handicapped students (*Battles v. Commonwealth; Georgia Association for Retarded Citizens v. McDaniel; Kruell v. New Castle County School District*).

Similarly, development of educational programs of benefit to severely handicapped students required reorganizing service delivery models to include a wide range of related services in the classroom as part of the educational program (*Tatro v. Texas*).

Taking the legal mandate that handicapped children be educated with non-handicapped children and applying it to those most severely handicapped, including those formerly placed out of public schools in institutional programs required the serious address of integration of all handicapped children in a variety of school and community based settings (*New York Association for Retarded Citizens v. Carey; Campbell v. Talladega County Board of Education; Roncker v. Walters*).

The *PARC* case and its enforcement history illustrates the evolution of judicial involvement from procedural and formal access issues to the substantive requirements for quality education. The *PARC* enforcement action since 1974 on behalf of severely handicapped students has occurred in three stages:

1. Actions for damages, contempt and enforcement to establish that effective education for severely handicapped students in public schools is lacking and to create the minimum necessary conditions for effective education for severely handicapped students;
2. court-supervised implementation of various school programs designed to demonstrate effective education for severely handicapped students; and
3. follow up litigation designed to enforce state-of-the-art requirements—including teacher training requirements of the *PARC* court decree and federal law.

The *PARC* decree, like P.L. 94-142, provided for procedures to enable parents to participate in and challenge decisions on educational placement and program. Those due process procedures, although technically sufficient to raise issues of quality such as comprehensiveness of curriculum, competency of teaching personnel, adequacy of therapies and related services, were useful only to challenge educational placement. Analyses of the due process hearings and the decisions of the hearing officers in Pennsylvania confirmed the limitations of the procedural protections. Hearing officers considered issues of quality beyond their jurisdiction. Parents who raised issues concerning appropriateness consistently lost. The due process hearing structured under *PARC* and P.L. 94-142, effectively distorted the mandate of the law to remedy cases of inadequate schooling and limited due process redress to those children misclassified, misplaced or excluded from services. The early and still continuing emphasis, upon procedural dimensions of the law is largely responsible for growing judicial involvement in the substance and content of special education (e.g., the appropriateness of the child's education).

In light of the legal requirement that the education provided to severely handicapped students be appropriate, and in the words of the United States Supreme Court be "calculated to yield real educational benefits" (*Rowley*), it is evident that an administrative procedural system that avoids quality issues will by default invite court address and redress. Court action to enforce the rights provided under the *PARC* decree became necessary in large part because local school officials, state officials—and to a certain extent the court monitors—put off basic questions of what was necessary to provide an appropriate education for severely handicapped children. Those questions were left to be resolved by procedural approaches such as the IEP, the due process hearing and administrative appeal.

The *PARC* enforcement action began in 1974 as a suit for damages on behalf of two severely handicapped brothers, David and Walter Fialkowski (*Fialkowski v. Shapp*). Under the *PARC* decree, both boys had been placed in a class for the severely and profoundly impaired in the Philadelphia School System. The Fialkowski parents objected to the program offered; they used the due process procedures and lost. Their complaint about the program concerned the quality of education provided by the school district of Philadelphia. Their sons, they alleged, received no education or training "appropriate to their personal needs." The Fialkowski brothers were taught—or at least the classroom teachers purported to try to teach them—academics. The program they participated in for three years—later characterized at trial as "play-school"—survived the minimal scrutiny of the administrative hearing officer who found the class placement in compliance with the *PARC* decree.

The state of Pennsylvania and the School District of Philadelphia sought to have the Fialkowski case dismissed on the grounds that there was no constitutional right to an appropriate education and that their complaint should not be resolved by a federal court, but by the *PARC* due process procedures. The Court in a pre-P.L. 94-142 decision refused to dismiss the case stating:

> The *PARC* procedural safeguards may prevent total exclusion from school; they may not be adequate to prevent total exclusion from education (*Fialkowski v. Shapp*).

The important distinction between being in school and receiving an education—a distinction that is just as explicit in P.L. 94-142—provided the basis in *PARC* for federal court remediation of the quality issues raised in the Fialkowski complaint.

In 1977 the *Fialkowski* case, as a petition for contempt and enforcement, was brought to trial in federal district court before Judge Edward Becker, the managing judge for the three judge *PARC* court. During the trial, experts in the education of the severely handicapped reviewed the educational programs of Walter and David Fialkowski and testified about the implementation of programs for the severely handicapped during the first five years of the *PARC* decree (1972–1977). Their opinion was that Walter and David Fialkowski, as well as other children assigned to classes for the severely handicapped in Philadelphia, had not received an education from which they could benefit or in the words of the decree, an education "appropriate to their learning capacities." The recounting of the *PARC II* proceedings from 1977 to 1982 is based upon transcript of trial (August 1977 and June 1981) and Transcript of Court Conferences 1978–1980.

Comparing the educational programs of the Fialkowski's with professional knowledge about what is necessary to effectively educate the severely handicapped person (i.e., the state-of-the-art), the experts found that the programs offered were and could not be of benefit because *inter alia* they lacked multidisciplinary evaluation, they lacked professionally acceptable individual education plans and they lacked curriculum addressing basic life skills. The experts also found no systematic instruction, inadequate teacher preparation and exclusion of severely handicapped persons from vocational education. After a week of testimony it was clear to the court and the parties that the requirements of the *PARC* decree and in prospect P.L. 94-142 could not be met in Philadelphia without putting in place a comprehensive remedial program. With the consent of the state defendants and school district, Judge Becker adjourned the court hearings and convened regular monthly conferences to oversee the school district's renewed undertaking to implement the *PARC* decree and to mediate disputes concerning implementation. During 1978 and 1979 over a period of sixteen months of regular meetings with all parites, the School District embarked on a "crash program" to institute multidisciplinary assessments and to develop professionally acceptable individual education plans. In addition, with consultation from outside experts, the School District undertook to establish a "life skills program" in a high school setting and to replicate the life skills model in high schools and middle schools throughout the city. During the mediation period of *PARC II* the court established a Special Education Action Committee, a Parent-to-Parent Hot line and mediated hundreds of complaints and disputes concerning transportation, the therapies, state monitoring, parent training, and school exclusion.

STATE-OF-THE-ART REQUIREMENT

Although the court's regular mediation conferences facilitated access to schooling for handicapped children (e.g., assessments, formal IEP's, transportation, timely enrollment of first year students), petitioners concluded that the initial, continuing and central matters addressed in the Petition for Enforcement—i.e., the introduction of state-of-the-art educational programs for severely handicapped children by adequately prepared and trained teachers in age appropriate, integrated settings—was not to be achieved through continued mediation. Therefore, Petitioners requested and Judge Becker granted the request for a return to trial of the Enforcement Action.

Trial resumed on June 1, 1981. Petitioners presented parents, school officials and seven prominent experts involved in the education of the severely handicapped. Their collective testimony showed, and similar studies by the school district confirmed, that the accomplishment of the formalities of multidisciplinary assessments and individual education plans as required by P.L. 94-142 did not yield education from which the 600 children assigned to classes for the severely handicapped could benefit.

The experts for both sides found IEP's in place, but no systematic instruction taking place. They found adequate resources in terms of numbers of teaching personnel (with the exception of therapists) but no intensity of instruction and excessive dead time. The instruction observed was generally not functional, not individualized, not systematic and lacked a multidisciplinary approach. Students, regardless of where their classes were located, had no interaction with non-handicapped peers. In-service training for teaching personnel was virtually non-existent and teachers and aides did not possess the competencies necessary to teach severely handicapped children. The most serious deficiencies were in the areas of behavior management and systematic instruction. Vocational education opportunities for severely handicapped students were still non-existent. The high school life skills classes initiated by the school district were found to be superficial and counterproductive to learning life skills in natural environments.

The pre-trial reports of the school district, state and federal audits and the testimony of school district officials at the trial confirmed what Judge Becker characterized as "the most shocking indictment of a school system one could conceive."

Rather than contest the facts, the school district defense was framed in comparative terms. Their point was that Philadelphia classes for severely handicapped students were typical of classes across the country. Urban school districts generally, even those associated with the experts who evaluated the Philadelphia schools, did not measure up to the standards of quality of appropriateness that the experts set forth. Philadelphia represented the state-of-the-practice in education of the severely handicapped and could not be legally required to measure up to a state-of-the-art that was—defendants claimed—to be found only in richly resourced university affiliated demonstration settings.

During the trial, Judge Becker rejected the state-of-the-practice defense, ruling that the standards for appropriate education under the decree and P.L. 94-142 were not to be judged by comparison with educational practices in Richmond, San Francisco or other cities, but to be judged by comparison with the state-of-the-art, i.e., what professional knowledge has demonstrated effectively works to teach severely handicapped students.

After two weeks of testimony and submission of hundreds of documentary exhibits which evidenced fairly strong experts' agreement as to what the state-of-the-art requirements were, the parties entered into a comprehensive consent decree incorporating state-of-the-art standards for appropriate education for severely handicapped students. (*PARC II*). Judge Becker approved the decree in June, 1982 and accepted jurisdiction to oversee a three year implementation period.

To accomplish the requirements of the *PARC II* settlement agreement within three years, defendant Philadelphia School District is required to:

1. Provide intensive in-service training for teachers, aides, occupational, physical and speech therapists and other support personnel engaged in the education of severely handicapped students.
2. Provide training to secure effective involvement of parents, guardians and surrogate parents in the education of severely handicapped students.
3. Provide all related services including occupational therapy, physical therapy and speech therapy necessary for the appropriate education of each severely handicapped student.
4. Establish demonstration and model programs and transfer the practices and results of those programs to all programs for severely handicapped students.

The Defendant Pennsylvania Department of Education is required to:

1. Provide the funding for fiscal years 1982, 1983 and 1984 in aid of implementation of the agreement.
2. Monitor educational programs for severely handicapped students, and identify any deficiencies and assure correction.
3. Disseminate the results of the programs, practices and materials developed under the agreement to enable school districts to adopt new and promising educational practices in the education of severely handicapped students.
4. Provide technical assistance to the School District in the delivery of vocational education to severely handicapped students.

Other important features of the agreement include:

1. The establishment of a ten person Professional Advisory Group who are skilled and experienced in state-of-the-art education for severely handicapped students to aid in the implementation.
2. The creation of three positions to direct the implementation to be filled by professionals in the field of education for severely handicapped students.
3. Particular planning requirements for vocational education for severely handicapped students.

4. The development of compensatory education options for all severely handicapped students 15 years of age or older.

Federal courts, when presented with claims of systematic violation of educational rights such as presented to Judge Becker in *PARC II*, have entered orders speaking to state-of-the-art requirements. For example, Judge Vance, in *Campbell v. Talladega County Board of Education* made findings as to what appropriate education for a severely handicapped student should consist of, including the necessary curricular elements, where and how they should be delivered and entered an order requiring both the state education agency and local school district to supply the necessary schooling and conditions (trained teachers and staff). As to the school district's existing program, the court wrote:

> After carefully weighing the testimony, this court finds that [plaintiff's] program fails in design and execution to further his progress in attaining such self-sufficiency as he may be capable of. As the program stands at present, it does little more than to occupy his time with activities devoid of educational justification. While the program may not be, . . . an actual impediment to progress, it is ill-suited to impart to Joseph any functional or communicative skills which might, to whatever degree, increase his independence. The court finds that Joseph's program thus fails to meet even a minimally stringent standard of appropriateness" (*Campbell v. Talladega County Board of Education*, 518 F. Supp. at 54).

The court's remedy included state-of-the-art relief. The court ordered the school district to provide instruction to focus upon the acquisition of functional skills in four curricular areas: daily living activities, vocational activities, recreational activities, and social and community adjustment. In view of the court finding that the severely handicapped student had "virtually no contact with non-handicapped students outside of his lunch period and even then such contacts are few" and was, "not placed into contact with non-handicapped students to the maximum extent appropriate," the court ordered the school district to, "provide . . . significantly increased contact with non-handicapped students" preferably by moving the class of severely handicapped students into a main high school building. To assure that substantive changes in educational programs were accomplished, the court ordered that the plaintiff's teacher and special education administrator, "be *trained* in the techniques essential to an appropriate program."

To make clear the state-of-the-art court order, Judge Vance suggested that an acceptable approach to implementation would be to, "insure the attendance of plaintiff's teacher and special education coordinator at the training program at Teaching Research of Monmouth Oregon" and to "engage the services of Teaching Research . . . in the development of a new appropriate IEP."[1] Like the orders in *Campbell* and *PARC II*, a number of court orders or approved remedies entailing state-of-the-art requirements give prominence to the requirement that teachers be trained.[2]

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[1] The Court described, Teaching Research as having a " 'model' training program for administrators and teachers serving severely handicapped children" with expertise "in the development and use of model programs and curricula for severely handicapped children."

The state-of-the-art mandate, particularly its training dimension, has two statutory bases:

1. Federal statutes P.L. 94-142 and Section 504;
2. State statutes

As to the first basis, P.L. 94-142, the teacher-preparation and continuing education duties are the most overlooked provision of this law. The statutory provision, 20 U.S.C. 1413(a)3, imposes two duties:

> (A) the development and implementation of a comprehensive system of personnel development which shall include the *in-service training* of general and special educational instructional support personnel, detailed procedures *to assure that all personnel* necessary to carry out the purposes of this Act *are appropriately and adequately prepared and trained* in effective procedures for acquiring and disseminating to teachers and administrators of programs for handicapped children significant information derived from educational research, demonstration and similar projects, and (B) adopting where appropriate, *promising educational practices and materials* developed through such project. (emphasis supplied)

This provision is a direct national statutory command in the area of teacher education and effective schooling, requiring the use of state-of-the-art rather than the state-of-the-practice. Simply put, the statute requires that if there is a practice which has been done elsewhere and worked, a state education agency or local school district cannot use one that has not been done before or does not work.

The school codes of at least 21 states carry provisions like Pennsylvania's 24 Pa. Stat. Ann. §15-1512, requiring that:

> The board of directors in every school district . . . shall arrange a course of study adapted to the age, development and needs of the pupils.

These school codes contain not only this central duty, but a fabric of specific provisions phased in terms of "adapted to . . . needs," "suitable" or "proper" to educational achievement. Such provisions and the statutory fabric of existing schools comes from the central underpinnings of the duty to use the state-of-the-art. Analysis of these statutes, their legislative and social histories, their interpretation and application by state courts, and their use administratively by state school agencies and districts yield a useful statement and exemplification of state-of-the art duties that supports and reinforces the P.L. 94-142 duty.

For example, in *Hendrick Hudson Central School District v. Rowley*, the United States Supreme Court was called upon to construe the word "appropriate" in the statutory duty imposed by P.L. 94-142 upon states and districts to provide a "free appropriate education" to all handicapped children. The Court held that "appropriate education" meant "calculated to yield [real] educational benefits." Although this decision on judgment was for Amy Rowley, a rejection of the lower court's view that she was entitled to particular elements in her education which would "maximize" or "equalize" her potential accomplishment. The Supreme Court's judgment that schooling must "be calculated to yield real educational benefits" would, if applied to the typical education program for severely handicapped children, result in the changes ordered for *PARC II*, *Campbell* and other cases.

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[2] *Matti T. v. Holladay*, 3 E.L.H.R. 551:109 (N.D. Miss. 1979) (para. 15); *Jose T. v. Ambach*, 3 E.L.H.R. 551:412 (E.D.N.Y. 1979); *Frederick L. v. Thomas*, 3 E.H.L.R. 551:569 (E.D. Pa. 1982); *Doe v. Grille*, 3 E.H.L.R. 551:285 (N.D. Ind. 1979).

The Congress in P.L. 94-142 had given meaning to what it thought constituted an "appropriate education." Section 1413(a) of that Act was not directly at issue in the *Rowley* case; nonetheless, the Supreme Court took occasion to notice and call attention to it. In words which patently recognize the relationship of state-of-the-art to "appropriate" or "proper" or "suitable" schooling, Justice Rehnquist's Opinion for the Court stated:

> The Education for All Handicapped Children Act expressly charges states [and local education authorities] with the responsibility of acquiring and disseminating to teachers and administrators of programs for handicapped children significant information derived from educational research, demonstration and similar projects, and adopting, where appropriate, promising educational practices and materials.

The state-of-the-art duty and its implications for forcing the use and distribution of new technology is not a radical or recent role for the courts. The role of the court in these matters, if not familiar, is time tested. It is most clearly illustrated in the opinion of Judge Leonard Hand in the *T. J. Hooper* case.

T. J. Hooper was a tug boat that got into trouble in the Atlantic Ocean off the east coast shore when a storm suddenly arose. At that time, the late 1920's tugs along the Atlantic coast relied for warning of sudden dangerous storms upon hand signals from the shore. Radio had been introduced but it was used by only a few tug boats. T. J. Hooper did not use a radio. Had the master used a radio, he would have known of the storm, would have sought cover, and the injury to life and property that occurred would have been avoided. The question in the case was, what was the duty of the T. J. Hooper? The award of damages to the people who themselves and whose property had been injured was based upon the answer to that question. Judge Hand wrote for the court, as follows:

> is it then, a final answer that the business had not yet generally adopted receiving sets? There are, no doubt, cases in which the courts seem to make the general practice of calling the standard of proper diligence. Indeed, we have given some currency to that notion ourselves. In most cases, reasonable prudence, is, in fact, common prudence, but strictly speaking it is never its measure. A whole calling may unduly lag in the adoption of new and available devices. A calling never may set its own tests, however persuasive by its usages; that role falls to the courts. 60 F.2d. 737 (2d Cir. 1932)

As to receiving sets, some tugs had them, some did not. The most that can be said is that they had not yet become general. The court held that in the presence of important matters, the obligation is not to share the state-of-the-practice, but to use the state-of-the-art.

SUMMARY

In the ten years experience the courts have had with the right to education and briefer time yet interpreting P.L. 94-142, much of the litigation after the initial round of exclusion cases, has affected severely handicapped students only marginally. However, the history of *PARC* and the recent Supreme Court interpretation of P.L. 94-142 in *Rowley* make predictable that judicial oversight of the important quality dimensions (what is taught, how, and where the teaching takes place) of education for the severely handicapped will be available to parents and advocates. The extent to which the courts will exercise this oversight depends largely on whether the public schools, like the tugboat operators of 50 years past, "underly lag in the adoption of new and available devices", and in doing so fail to effectively educate students with severe handicaps.

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SECTION THREE/
PROGRAMS FOR SMR POPULATION

CHAPTER 4/
SEVERELY MENTALLY RETARDED YOUNG CHILDREN

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Classification
Identification
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Severely mentally retarded young children do not often receive focused attention in the professional literature, perhaps because they constitute such a small proportion of both the preschool and handicapped populations. As with older handicapped children, they have been classified by a number of different terms: severely retarded, profoundly retarded, trainable, custodial, and severely developmentally disabled. Often, these children have multiple physical and health impairments which are readily identifiable at birth. In reality, severely retarded preschool children constitute a diverse population because of differences in age, severity of handicapping condition, and associated disorders. As with other preschool-age handicapped children there is supporting evidence (Bricker & Dow, 1980) and widespread agreement that early intervention is effective, even though definitive efficacy research is lacking.

CLASSIFICATION

Severe mental retardation is a condition that exists in a small proportion of the population, approximately three or four people per thousand (Tarjan, Wright, Eyman, & Keeran, 1973; Haring, 1982). Theoretically, the severely retarded are that portion of the population who fall four or more standard deviations below the mean on measures of intellectual performance, and constitute three to four percent of all retarded people and 0.1 percent of the total population. In fact, this population is reported to be more than double the theoretical frequencies (Dingman & Tarjan, 1960; Tarjan et al., 1973; MacMillan, 1977).

Determining criteria for classification of mentally retarded adults has been an issue of considerable controversy and discussion, resulting in some measure of agreement (MacMillan, 1977). However, clarification of the criteria for preschool-age children has received less attention, perhaps because there are inherently more difficulties in applying the same criteria to young children. Several factors contribute to this difficulty. First, it is commonly acknowledged that measures of intellectual ability in young children lack both reliability (Lewis, 1976) and predictive validity (McCall, 1979). Second, there are no agreed upon standards of adaptive behavior for preschool-age children (Mercer, 1973). Third, with young children, it is difficult to differentiate between intellectual and adaptive behavior (Saarni, 1978; Bricker & Carlson, 1981). The lack of reliable and valid assessment procedures for preschool intellectual and adaptive behavior, and the difficulty in clearly differentiating between the two, combined with a general belief that it is potentially destructive to classify young children as severely retarded, lead many professionals to avoid labels such as severely retarded and to substitute less noxious labels such as developmentally delayed.

A more functional approach to classification has been proposed (Sontag, Smith, & Sailor, 1977; Sailor & Guess, 1983) in which children would be classified and assigned to programs based on the type of instruction needed.

Headstart training materials advocate a similar approach, suggesting that teachers view severe handicaps on the basis of ". . . how the children function, what and how they learn, and how much time they need to learn" (Lynch, Simms, von Hippel, & Schuchat, 1978).

IDENTIFICATION

Despite substantive issues in using classification standards developed for older children and adults, technical inadequacies in measuring intelligence and adaptive behavior in young children, and lack of specificity in alternative proposals, there are many severely mentally impaired infants and preschoolers. These children usually can be identified early, and professional agreement exists that they require intervention upon detection if the detrimental consequences of their handicaps are to be lessened.

Severely retarded and multiply handicapped young children are usually initially identified in one of several ways. First, prospective parents may be high risk, because of genetic, physiological, or environmental factors, for having children who may be severely retarded and/or have other handicapping conditions. For example, some syndromes such as Arthrogryposis, which is associated with severe retardation, are genetically transmitted by the parents (Smith, 1976).

Second, prenatal conditions may create a high risk for fetal damage and subsequent severely handicapped conditions. Maternal disease, trauma, toxicity, and severe malnutrition may all lead to atypical fetal development. The first trimester of pregnancy is a particularly susceptible time for fetal trauma that may result in physical and neurological damage, severe retardation, and associated disorders (Babson, Benson, Pernoll, & Benda, 1978). Often, physical disorders as well as mental retardation result from prenatal damage.

Third, infants may be determined at birth to have medical syndromes or physical malformations ordinarily associated with retardation. Professionals should be careful not to assume, however, that a particular syndrome inevitably leads to severe retardation. Rather, the detection of a syndrome should lead to referral, further evaluation, and, where appropriate, early intervention services. As a case in point, children with Down syndrome were once considered to be severely retarded and were often committed to custodial programs. In many cases their syndrome, coupled with a lack of effective intervention did lead to severe retardation. In recent years, however, it has been demonstrated that many individuals with Down syndrome can learn readily and function near normal levels of intellectual and adaptive behavior if they receive proper educational intervention beginning in the earliest months of life (Hayden & Haring, 1976; Ludlow & Allen, 1979).

A fourth way of identifying children is through developmental assessment. Actually, children identified as high risk in the previously described ways, are ultimately evaluated through developmental assessments. Infants and preschoolers are usually considered severely delayed and potentially severely retarded, if they perform at developmental levels of less than one-half to one-third that expected for their age on cognitive measures or measures relating to cognitive performance. Such measures may be norm-referenced and standardized, such as the Bayley Scales of Infant Development (Bayley, 1969). They may be based on a particular developmental theory, such as the Psychological Scales of Ordinal Development (Uzgiris & Hunt, 1975), which are Piagetian based. Or, they may be developmentally based and criterion- or program-referenced, such as the Uniform Performance Assessment System (Haring, White, Edgar, Affleck, & Hayden, 1980).

Few early intervention programs serve only the severely mentally retarded. Most programs also serve mildly and moderately retarded children as well as children with other handicapping conditions. Consequently, the distinctions between moderate and severe retardation, and between retardation and other handicapping conditions, are often unimportant in terms of eligibility to receive services. The important issue is whether a child is judged eligible for services, and subsequently receives appropriate and effective programming.

CHARACTERISTICS OF SEVERELY MENTALLY RETARDED YOUNG CHILDREN

Severely retarded young children exhibit great variability, partly because of the population's high rate of medical problems, physical anomolies, and sensory and motor impairments. Some severely retarded children show normal growth patterns, while others deviate markedly. Some have adequate hearing and vision, while others have a significant hearing or visual deficiency. Some demonstrate excellent motor skills, while others are severely neurologically damaged and cerebral palsied. Some communicate through speech or sign language while others lack communication skills. Some are socially responsive and active, while others are totally withdrawn. To presume that severely retarded preschoolers are more alike than different would be erroneous.

Age is also an important factor affecting the characteristics of severely retarded preschoolers. Even though they progress developmentally at a much slower rate than their peers, the preschool years are still a period of relatively rapid change. The characteristics a child exhibits at one age are likely to be substantially different than those exhibited at another age. Even though the chronological development of an individual child rarely matches a predetermined sequence, a sample listing of characteristics an individual might exhibit at different age levels is presented in Table 4.1 to illustrate how a severely retarded child might progress from one age to the next. It should be remembered that if a child has additional handicaps or impairments, he or she might deviate markedly from the described behaviors.

HISTORY OF DEVELOPMENTS RELATING TO PRESCHOOL SEVERELY MENTALLY RETARDED CHILDREN

Historical events which have affected services for severely retarded young children cannot be easily differentiated from events relating to older severely retarded or to less severely handicapped preschool-age children. Consequently, many historical topics relating to preschool severely retarded overlap with those of the other groups.

Prior to 1950, the treatment of preschool retarded children did not differ substantially from that of many older retarded individuals. Primarily, there were two alternatives: either children remained in their natural homes or they were placed in institutions. Few preschool or school-age severely retarded children were provided educational placements in public schools. Some residential placement centers existed, but were affordable mainly by the wealthy.

Parent and Professional Organizations

In 1950, numerous groups of parents of handicapped children combined to form the National Association of Parents and Friends of Retarded Children (MacMillan, 1977), which became the National Association of Retarded Children (NARC). The membership of this organization, now called the National Association of Retarded Citizens, has grown from 2,000 in 1950 to 151,000 in 1983. A majority of the early members were family members of severely handicapped individuals.

The most substantial contributions to NARC were in the areas of program development (including preschool programs for the moderately and severely handicapped), advocacy for retarded children, sponsoring litigation, influencing legislation (Roos, 1975), and provision of support for its members. The contributions of this group have been substantial.

Important professional organizations include the American Association of Mental Deficiency organized by medically-oriented professionals in 1876, and the Council for Exceptional Children which has two divisions for those interested in severely retarded children. The Division on Mental Retardation was first organized in 1963 and it began publishing the journal *Education and Training of the Mentally Retarded* in 1966. In 1977, it published its first special publication, which addressed the severely and profoundly handicapped and contained several articles specific to preschool severely handicapped. This same division has sponsored the distribution of this volume. The Division of Early Childhood was organized in 1973. It publishes a quarterly journal on early intervention, and advocates for all preschool handicapped, including the severely retarded.

An organization which has recently exerted influence in regard to severely retarded young children is The Association for the Severely Handicapped. The group was organized in 1974 by professionals involved primarily in education and training of personnel to work with severely and profoundly handicapped people.

Public Policy

Numerous laws affecting service to the handicapped have appeared since 1950. In addition, there have been many notable court cases which have influenced the form of the current service delivery system. These are reviewed by Noel, Burke, and Valdivieso in this volume. One particular law has benefitted preschool retarded children directly. In 1968, Congress passed Public Law 90-538, the Handicapped Children's Early Education Assistance Act (Harvey, 1977), establishing the Handicapped Children's Early Education Program beginning with funding of 24 projects, several of which included severely retarded children.

Public Law 94-142 led to mandatory public education for handicapped children from ages three to twenty-one. However, states were excused from serving handicapped preschoolers below the age at which nonhandicapped children attend public school. Children under the age of three were exempted from the requirement altogether. This policy was partially rectified with passage of the Education of the Handicapped Act Amendments of 1983, Section 623. The amendment permits services to birth and authorizes funding for each state to assist in the planning, development and implementation of a "comprehensive delivery system for provision of special education and related services to handicapped children from birth through five years of age." This legislation is a step toward providing preschool handicapped children the same rights to intervention as those of school-age.

History of Service Delivery

In the 1950s, parent groups established programs for preschool handicapped children, some private agencies provided programs, and some public agencies provided a limited range of services. Throughout the 1950's and early 1960's there was a gradual increase in the number and sophistication of programs. Many programs were considered respite, some were viewed as places to make children happy, some were stimulation or activity oriented, and a few were aimed at educational or therapeutic intervention. Early orientations were largely medical and/or psychiatric.

With the advent of the Handicapped Children's Early Education Pro-

Table 4.1 Representative Developmental Behaviors and Ages at Which They May Occur in Severely Retarded Children

	Independent Functioning	Physical	Social	Communication
Birth to 6 months	— Engages in functional sucking behavior — Needs support at shoulders while being dressed — Has established feeding schedule	— Lifts head and chest using forearms as support — Rolls over (front to back)	— Identifies others	— Random sounds — Moves eyes toward sound source — Smiles spontaneously — Babbles or coos in play when alone or talked to
1 year	— Reaches for cup — Picks up spoon	— Turns from back to side — Pulls to sit — Reaches with two hands to approach toy	— Reaches for familiar person — Discriminates strangers — Plays sitting propped in play area for 10–15 minutes — Plays actively with small toy	— Turns head to voice — Coos, chuckles, and laughs aloud — Vocalizes when spoken to or pleased — Babbles using series of syllables
2 years	— Takes solid foods well — Needs support at lower spine while being dressed — Reaches for food when being fed	— Rolls from back to stomach — Crawls on all fours — Stands briefly when hands are held — Sits by self	— Pats and smiles at reflection in mirror — Clings to known adult — Bites and chews toys — Cooperates in games with adults	— Responds by turning head, stopping movement to name and "no" — Plays "peek-a-boo" type games — Vocalizes deliberately as a means of interpersonal relationship — Vocalizes single syllable

3 years	—Drinks from cup with little assistance —Puts finger food into mouth —Helps constructively when being dressed	—Sits well —Walks unsteadily —Throws ball —Rolls ball back and forth in game —Picks up small object with pincer grasp	—Demands personal attention —Walks about room unattended	—Gives objects on request —Turns to own name —Indicates wants by gestures and vocalization —Imitates words
4 years	—Chews and swallows without spilling —Pulls shoes off —Can unzip zipper —Bladder control usually attained	—Crawls up stairs —Walks well —Runs stiffly upright —Pushes and pulls large toys	—Refers to self by name —Alternates between clinging and resistance to familiar adults —Constantly explores environment —Plays with other children —Handles everything within reach	—Points to familiar persons, animals, and toys —Follows one-step directions —Jabbers loudly using wide range of inflection and phonetic units —Says four to five vocabulary words
5 years	—Asks for food and drink when hungry and thirsty —Takes bites from spoon —Pulls on simple garments, shoes, hat, and mittens —Indicates toilet needs	—Kicks ball —Takes steps up stairs	—Identifies self in mirror —Names possession of others and to whom they belong —Plays interactive games	—Combines gestures and utterances to make wants known —Uses expressive vocabulary of at least 15 words —Names common objects
6 years	—Gets drink unassisted —Spoon-feeds self without spilling —Undresses completely —Follows mother around house and copies domestic activities in play	—Fills and dumps containers of sand —Balances on walking board —Pedals tricycle	—Cries, pouts when attention shown to other children —Demands mother's attention —Brings favorite toy to school, but refuses to show it —Plays interactive games—tag	—Matches familiar objects —Talks to self continually during play —Constantly asking names of objects —Uses expressive vocabulary of 50 or more words

NOTE: Table 4.1 represents a sample listing of characteristics a severely retarded individual might exhibit at different levels in his/her development. If a child has additional handicaps or impairments, he/she might deviate markedly from the described behaviors.

gram, a number of model programs developed that included severely handicapped preschoolers and a few developed that served primarily the severely handicapped. They generally included interventions that were aimed at creating developmental and behavioral gains in children.

Technological Change

Intervention technology has progressed steadily since the 1950's. Early preschool programs were often activity oriented, aimed toward the goal of entertaining the children. Later, curricula were developed for developmental or functional areas, such as self-care, motor development, and language skills. Subsequently, curricula were developed with theoretical bases, with behaviorally stated objectives, and with task-analyzed sequences. Recent developments include the careful use of natural interactions to instruct children, and the functional analysis of the environments in which children live.

Corresponding changes have occurred in identification and assessment technology. In the early 1950s, the few assessment instruments that existed were general ability measures, and were not appropriate for the severely retarded child. The 1960s and 1970s saw the development of specific screening and developmentally sequenced tests, followed by development of curriculum-related assessment instruments, some of which were designed specifically for severely and multiply handicapped children.

Intervention technology has changed from provision of unstructured programs and giving "love and attention" to more careful arrangements of the instructional environment. Recently, there has evolved an instructional technology of precise objectives, modeling, cueing and prompting, specification of desired responses and response patterns, reinforcement, feedback, and correction procedures. Early such efforts were mechanistic. Later interventionists were able to use such precise procedures in natural environments and exchanges with severely handicapped children. Evaluation has evolved from subjective judgements about child progress and gross intellectual measures to precise evaluation using instruments and procedures that allow descriptions of individual progress and program effectiveness.

In summary, there have been significant changes relating to preschool handicapped children since 1950. Parent and professional organizations have been established and have assumed an increased role in personnel development, research, dissemination, leadership, and advocacy of free appropriate public education. Congress passed the Handicapped Children's Early Education Assistance Act, resulting in an increase in number and quality of early intervention programs serving the severely retarded. A segment of society now views severely retarded persons as benefiting from intervention, as being a responsibility of society, and as having the right to treatment.

COMPONENTS OF SUCCESSFUL PROGRAMS

An understanding of the components of successful early intervention programs has evolved in the past 15 years, from general early intervention literature, from analyses of HCEEP model projects, and from descriptions of a few projects specifically serving the severely handicapped. The resulting information is likely to be applicable to programs primarily serving young severely mentally retarded children, even though many programs do not explicitly document their procedures for this population.

Bricker (1982) has generated a list of questions to assist early intervention personnel in designing and implementing their programs. These questions address the areas of: a) planning for identification of children to be served, b) developing a statement of the project rationale and operational approach, c) describing curricula and strategies for determining intervention objectives, d) specifying how the selected objectives will be met, e) developing a system for monitoring effectiveness, f) specifying procedures for children's transition into next environments, and g) providing a system for tracking children who have been enrolled. Consideration of these guidelines would enhance the probability of designing an effective early intervention program.

Several early intervention programs have received approval by the Joint Dissemination Review Panel (JDRP) of the U.S. Department of Education and the National Institute of Education, which evaluates the practical and statistical significance of model projects. The JDRP-approved programs exhibit characteristics consistent with Bricker's guidelines for development and implementation. These characteristics, as described by Filler (1983) are:

1. A philosophical basis on which a program is developed.
2. A clearly specified curriculum.
3. An appropriately trained staff.
4. Parent and family involvement.
5. Program evaluation.

Each of these characteristics is considered in some detail below.

Philosophical or Theoretical Base

The rationale or theory underlying a program provides the necessary foundation upon which other program decisions can be made, such as selecting curricula and programming strategies, establishing criteria for making instructional modifications, and formulating criteria for selection of personnel

(Bricker, 1982). Filler (1983) describes three theoretical bases upon which early intervention programs are based: a) developmental-quantitative, b) developmental-qualitative, and c) functional approaches.

The developmental-quantitative approach rests on the premise that curricular content should be derived from carefully specified listings of developmental behaviors exhibited by nonhandicapped children. According to Filler, the Experimental Education Preschool at the University of Washington (Hayden & Dmitriev, 1975; Gentry & Adams, 1978) and the Portage Project (Shearer & Shearer, 1976) are based on this approach.

The developmental-qualitative approach emphasizes an infant's behavior in relation to objects and events (Filler, 1983). Examples of programs which adhere to this philosophy are the preschool program at the University of Oregon's Center on Human Development (Bricker & Sheehan, 1981) and the infant program at Western Carolina Center (Dunst, 1981).

Sailor and Guess (1983) describe the functional approach in some detail. This model proceeds on the premise that the curriculum should consist of content that is functional in a child's current or next environment. Vincent, Salisbury, Walter, Brown, Gruenewald, and Powers (1980) apply this model by incorporating into their curriculum, skills identified as necessary for infants in their next environment.

Curriculum

A well-defined curriculum is the second component of successful early intervention programs. Predictably, as educational services for infants and young handicapped children have increased in number and improved in quality, so has the demand for curricula and teaching materials.

Early curricula were general in nature, consistent with the philosophy of the times. Hunt (1961), for example, suggested that the purpose of early childhood intervention should be to provide "massive general experiences" to young children. This concept is reflected in the "infant stimulation" programs of the 1960s and 1970s. However, these concepts were not as relevant when applied to the handicapped, and specifically to the severely retarded, because of the inability of the severely retarded learner to adequately benefit from general learning experiences alone. Curricula were then developed which were based upon developmental milestones, theories of normal child development, or sequential analyses of early childhood tasks. These curricula include developmental sequences from which teaching targets can be derived or from which the most appropriate teaching tasks can be selected based on a child's functioning environments. Examples of curricula which have been shown to be effective and which have been widely used include the Portage Guide to Early Education (Bluma, Shearer, Frohman & Hillard, 1976), The Teaching Research Curriculum for the

Moderately and Severely Handicapped (Fredericks et al. 1976), Teaching Your Down's Syndrome Infant (Hanson, 1977), Project Memphis (Quick, Little, & Campbell, 1974), and Learning Accomplishment Profile (LAP, 1974).

With numerous curricula being developed, it is understandable that professionals differ in their opinions regarding the merit of one curriculum over another (see Brinker, this volume). There is some agreement that curricula appropriate for the mildly handicapped child will be different than that applicable to the severely handicapped or severely retarded child (Bailey, Jens, & Johnson, 1983).

A curriculum used with a severely retarded young child may be substantially modified in light of environmental considerations. Since these children are served most often in home settings, or a combination of center-home settings, the specific environment may be of importance. The Kent First Chance Project (Ramey & Trohanis, 1982), a hospital affiliated program serving only severely retarded children from three months to eight years of age, has emphasized environmental factors in curriculum selection by combining developmental and educational intervention with an emphasis on environmental responsiveness.

The assessment of severely retarded children traditionally has been conducted independently of curriculum objectives. In recent years more attention has been given to relating assessment to curriculum content (Bagnato & Neisworth, 1981; Gentry & Adams, 1978). Assessment instruments have been designed which provide an initial assessment of children's development, identify potential instructional targets, and which can be used in combination with other assessment instruments to conduct program evaluation. An example of such an instrument is the Uniform Performance Assessment System (Haring et al., 1980) developed at the University of Washington. The Consortium on Adaptive Performance Evaluation (1981) extended the concept, indicating that an evaluation process should assess the content which severely handicapped children are to be taught, allow for adaptive testing procedures to accommodate for sensory or motor impairments common to the severely retarded, and emphasize functional rather than strictly developmental aspects of specific behaviors. Subsequently, Bricker and Gentry (1983) have developed an assessment instrument which will be correlated directly with programming steps of a curriculum.

Staff and the Interaction Among Disciplines

Comprehensive intervention with young severely mentally retarded children is beyond the scope of any single discipline (Chinn, Drew, & Logan, 1979) because of the frequent occurrence of multiple problems, and significant adjustment needs of families. These multiple and diverse needs require the expertise of several disciplines. For example, a program may include educators for the ongoing provision of intervention services, medical personnel for health concerns, physical and occupational therapists for motor problems, communications disorders specialists for communication needs, and a psychologist for assessment and evaluation. Families themselves often assume a substantial or central role in the intervention process. A social worker or other support professional may be necessary to meet the needs of the family for support and integration of services. A lack of such integration can mean the fragmenting of service delivery, the overstimulation of the child and family, or development of competing programs of intervention (Harris & Tada, 1983).

Several approaches to team functioning have been used over the past two decades, called multidisciplinary, interdisciplinary, and transdisciplinary approaches. The multidisciplinary team approach (McCormick & Goldman, 1979), in which team members work mostly independently, was the earliest. The interdisciplinary team model includes an emphasis on communication among team members, a theoretical commitment to group decision making, and development of a unified service plan. Practically, the team typically meets on a regular basis to discuss findings and make recommendations. With the transdisciplinary approach (Haynes, 1976), professionals work jointly in assessment, analysis of findings, and provision of intervention services, and may include parents as active participants. McCormick and Goldman (1979) concluded that the transdisciplinary approach is the most appropriate model for serving severely handicapped children.

Sailor (1977) describes a modification of the transdisciplinary team model in a program for severely impaired children. With this model, the classroom serves as the center of assessment and service activity for the child. Members of the team work in the classroom rather than in separate diagnostic or therapy areas, and provide ongoing consultation to the parents and teacher.

Howard (1982) notes five characteristics essential in team members and team operation to achieve a cooperative effort: a) acceptance of differences in skills, b) acceptance of differences in approach, c) willingness of different team members not to try to know everything, d) an ability to call on other team members for their knowledge and assistance, and e) nonthreatening opportunities for discussing areas of concern and difference.

Parent Involvement

A fourth component seen as necessary for successful early intervention programs is parent involvement. There has been no general agreement in the field of special education about the most appropriate theoretical bases, program philosophies, curriculum models, intervention approaches, and models for staff interaction. Nor, is there convincing evidence that one approach is more effective than another. There is more agreement that parents should be involved in their children's programs, and considerable evidence that skills taught by professionals will be acquired more rapidly, generalize more readily, and maintain longer if they are also taught at home by the parents. For example, Fredericks and his colleagues (1974) have demonstrated that a systematic program by parents in conjunction with a school program can almost double the rate of acquisition of a particular skill.

Parent involvement has been insured through their political strength and the achievement of legal rights. Groups such as the National Association of Retarded Citizens were instrumental in securing the passage of Public Law 94-142 which has assured due process rights to parents of school-age handicapped children (Payne & Patton, 1981). These rights have set the pattern of parent involvement that has impacted participation at the preschool level.

The specific needs of the families of severely mentally retarded children have not been documented as differing from those of families of children with other handicaps. Perhaps there are few or no differences, or perhaps differences have not been detected because services for severely retarded children have not been differentiated from services for children with other handicaps.

At least four considerations are important to planning parent involvement program components. The first two contribute to and are frequently part of successful programs, and include a) acknowledging the potential emotional and stress responses associated with parenting a handicapped child, and b) individualization of programming for families. The second two have been emphasized more recently, and include c) recognition of the interaction among family members, and d) the application of family systems theory to parent programs.

Emotional Responses The diagnosis of mental retardation or other handicapping conditions can result in an extraordinary impact on the parents of a newborn. Parent reactions upon learning the news are well documented (Carr, 1974). These reactions may include shock, grief, confusion, and guilt (Dalton & Epstein, 1963). From another perspective they may include loss of self-esteem, shame, ambivalence, depression, self-sacrifice, and defensiveness (Roos, 1975). For more detail see Fredericks, this volume.

There are other particular stresses for parents associated with the birth of a handicapped infant, such as stress resulting from financial difficulties (McAndrew, 1976), marital discord (Farber, 1968), and the discrepancy between having a handicapped child and one that is typical of the cultural norms (Parke & Collmer, 1975). Beckman-Bell (1981) distinguishes between alterable and unalterable characteristics of children which can affect parent-child relationships. Unalterable characteristics, such as sex, physical appearance, and diagnostic category can contribute to the emotional response and/or stress level of parents. Alterable characteristics, such as caregiving demands, behavior problems, and social responsiveness, can, when left unattended, increase stress and impact the interactive relationship between parent and child. These characteristics are often the objectives of home intervention programs. Beckman-Bell recommends that professionals ascertain which characteristics cause parental concern and include these in individualized programs for the family.

It is likely that some emotional reactions of parents will be long-lasting and that others will recur or be occasioned by specific events. An understanding of the recurrence of emotional reactions can lead to increased professional acceptance of parents' responses to specific situations or new problems.

Professionals need to be cautious in making inferences or interpretations of parents' behavior and emotional reactions (see Fredericks, this volume). Turnbull (1978), both the parent of a handicapped individual and a professional, describes her reactions to current practices which emphasize the analysis of parental reactions such as guilt. She has indicated that in many training courses for professionals only limited attention is directed toward helping parents solve day-to-day problems. Such oversights can lead to further conflict and unsatisfactory relationships between parents and professionals.

Individualization of Programming A second important factor in successful parent involvement is the individualization of services for families. Shearer and Shearer (1977) assert, "If one of the project's objectives is to teach parents to teach the child, then it should be recognized that the teacher must individualize planning for both the child and the parent" (p. 233).

Several professionals emphasize direct training of parents. Fredericks, Baldwin, and Grove (1974) advocate training of parents to facilitate acquisition of skills by their children. According to Fredericks and his colleagues, there are several important elements of an appropriate parent training system: a) allowing adequate time for training, b) providing training appropriate to parents' levels of acquisition, c) incorporating a continuous system of feedback, and d) providing a simplified system of communication between teacher and parent.

Interactive Processes From the interactive process perspective, family interactions can be viewed as complex and dynamic, with individual members influencing other members (Cochran & Brassard, 1979; Hartup, 1979). Particularly important are mother-child relationships. Normally developing infants typically exhibit a variety of behaviors that are reinforcing to the mother. However, severely retarded infants may not exhibit them or may develop them at a much slower rate, and the mother's attachment to her infant may be adversely affected (Robson & Moss, 1970; Kogan, Tyler, & Turner, 1974). A successful intervention program that emphasizes small increments of growth in a young handicapped child may provide the parent with the reinforcers necessary to maintain a positive attachment.

The interactive approach also stresses the psychological needs of parents. For example, the Bromwich Parent Interaction Model (Bromwich, 1981) attempts to effect positive changes in a parent's feelings toward an infant. The instrument used is the Parent Behavior Progression, which contains six levels of parent affect and skill. After parents accomplish the first levels ("enjoys infant," "is sensitive observer of infant") they are trained to teach their children specific skills. The uniqueness of this approach is the emphasis on the parent-child relationship and the use of a defined sequence to measure important phases of the relationship.

Family Systems Theory Family systems theory (Haley, 1976, 1980) is an extension of the interaction process approach, and provides a conceptual framework for professionals working with families of handicapped children. This approach asserts that behavior is affected by context, and that behaviors can best be understood as part of the interactional sequences and patterns among people.

A structural approach examines the subsystems (marital, parental, and sibling) and how they are organized in relation to one another. Each family has a structure which includes a pattern of alliances, roles, and functions used to make decisions and carry out family tasks. The family structure can be mapped and described to enable intervention with potentially dysfunctional situations (Foster, Berger, & McLean, 1981). Also, an intervention with one of the subsystems may have an impact on other subsystems. For example, an intervention with a mother and a child may impact an entire family (Montalvo & Haley, 1973). Reciprocally, other subsystems within a family may contribute to or detract from the effectiveness of mother-infant intervention. For example, other siblings might make demands on a mother that preclude her systematic intervention with an infant. A systems approach has the potential of permitting a more individualized approach to family intervention. Since it can provide a set of concepts and techniques for evaluating and understanding families, it may result in interventions which are satisfactory to families and achieve a commitment by an entire family to a specific intervention approach.

The typical parent participation component in early intervention models focuses on teaching a child specific skills and on parent-child relationships. Such an approach is dyadic and does not consider the relationships among the subsystems within the family. Although rationale and theory may support the need for system considerations (Wahler, 1980), an approach to the entire family as a system has not become common practice in early intervention programs.

EVALUATION

Another component necessary to successful programs is comprehensive evaluation. Without evaluation, it is impossible to know if an intervention program is effective. Early intervention programs which have demonstrated their effectiveness have used various evaluation procedures described in publications of technical assistance agencies serving HCEEP model projects (e.g., the Technical Assistance Development System (TADS) operating from the University of North Carolina). Another source reviewing evaluation procedures in some detail is Bricker, Sheehan, and Littman (1981).

Suarez (1982) identified key factors essential to an effective evaluation plan. These factors include:

1. Focusing the Evaluation. Focusing can be achieved by determining the purpose of evaluation, the audience who will receive the results, and the individual components which merit evaluation within a project.
2. Planning Specific Evaluation Strategies. Planning includes formulation of evaluation questions, determining an evaluative approach, establishing data collection and analysis procedures, and, finally, developing criteria for using results.
3. Planning for Communication of Evaluation Results. The plan should include a statement of the purpose for communicating results, an indication of the audiences who are to receive evaluation results, and a description of the methods by which results are to be communicated.
4. Implementation of Evaluation. This component includes a determination of who will evaluate, how frequently data will be collected, actual data collection and analysis, and monitoring of the evaluation procedure.

In the past decade, cost analysis has become a frequently included element of program evaluation. With current economic constraints, early intervention programs have been challenged to produce evidence that they are cost effective. Some general assertions which are the results of these cost effectiveness studies include the following:

1. Children who participate in preschool programs require fewer special education services when they reach school age (Schweinhart & Weikart, 1981; Lazar & Darlington, 1982; Weiss, 1981).
2. Preschool services can benefit parents of handicapped children, e.g., the parent may not have to forego employment to care for the child (Takanish & Feshback, 1982).

3. Handicapped children who participated in preschool programs were later retained in a grade less often than children who did not have preschool programs (Lazar & Darlington, 1982).
4. Children who participated in preschool programs scored consistently higher on achievement measures (Lazar & Darlington, 1982).

A recent Colorado study (McNulty, Smith, & Soper, 1982) reported cost-benefit data for preschool programs according to severity of handicapping condition. This report concluded that severely handicapped children who received preschool services more often were placed in regular education programs than children not receiving such services. Of this group nine percent required no support services, while 24 percent required some support services.

Early intervention programs for severely retarded children should include an evaluation component directly related to project goals. Careful attention should be given to evaluation design, selection of appropriate evaluation instruments, timing of data collection, and dissemination of evaluation results. An evaluation plan should consider not only summative impact data, but also formative data which project personnel can use to modify program activities or individual intervention plans for children.

UNRESOLVED ISSUES

Several issues related to early intervention with the severely retarded child continue to be of substantial importance. One of those issues is the efficacy of early intervention for handicapped children and specifically with the severely retarded. Even though numerous research, evaluation, and cost effectiveness studies tend to support the benefit of early intervention, the results are sometimes inconclusive or tentative (Bricker, Bailey, & Bruder, 1984; Casto & Clarkson, 1983; Stevens, 1980). Such studies have rarely focused specifically on the severely retarded. This, coupled with the fact that some professionals challenge the ability of the severely retarded people to learn (Burton & Hirshoren, 1979a, 1979b; Sontag, Certo, & Button, 1979[1]) indicate a need for carefully designed studies that evaluate specifically with the severely retarded population the short-term and long-term effectiveness of early intervention, the cost effectiveness of different approaches, the relative effectiveness of different interventions, and the conditions under which they are most effective.

A second unresolved issue is society's failure to accord to the young severely retarded child the same intervention rights accorded to older

[1] Article by Sontag, Certo, and Button is a rebuttal.

handicapped children. There is no federal legislation that specifically assures the right of young severely retarded children to early intervention. Many states, through health, education, and/or welfare programs, provide intervention services, but children and families usually have little or no recourse if such services are not provided. A consequence of the lack of protective legislation is that many children and families do not receive services.

A companion to the above issue is the lack of fiscal support for early intervention programs. Federal support to states for early intervention services is less than five percent of the usual cost. At the same time, state allocations are often inadequate for even the limited number of children they serve. Because the severely handicapped cost more than other children to educate, they may be impacted even more by low levels of funding.

Where services for the severely handicapped children do exist, they are often fragmented. Parents must approach numerous agencies and resources to obtain essential services, many of which are not coordinated with each other. At the same time, existing patterns of service delivery make it difficult to provide services to severely handicapped preschoolers in integrated environments. Funding is provided only to serve the handicapped child, so normal peers often are not present. The provision of programs through public schools, preschools, and day care centers provides an alternative to segregated programs. Such programming will require flexibility on the part of funding agencies to allow a variety of service delivery settings and agencies.

There is consensus about the value of parent involvement in child programming. But the issues of what is reasonable to ask of parents, and what resources society should provide them are unresolved. For example, is it reasonable to ask all parents of retarded children to be teachers of their children? What about respite care? Evidence indicates that a major reason parents commit their young retarded children to alternate living arrangements is to alleviate stress on the family. What resources should society provide parents and families to enable them to keep their retarded children at home, rather than send them to foster placements, group homes, or larger institutions?

Evaluation of the effectiveness of early intervention with preschool handicapped populations, particularly those with severe biological impairments such as severe retardation, continues to be a concern among professionals. The results of reviews of efficacy studies (e.g., Bricker, Bailey, & Bruder, 1984; Stevens, 1980) are similar; numerous studies report positive evidence for the efficacy of early intervention, but methodological flaws and contradictory results weaken those conclusions. The major limitations of previous studies have been inadequate control in the evaluation or research designs, selection of inadequate or inappropriate outcome measures, and the failure to consider long-term outcomes. Efficacy studies with severely retarded children are needed which attend to these crucial concerns.

TRENDS

Future trends in early intervention will be a natural outgrowth of past and current practices. For example, advances that have occurred in assessment, curricular, and instructional technologies during the past two decades will be followed by continued refinements. Of significance will be the incorporation of these technologies into more naturalistic models of intervention. At the same time new technologies, such as use of microcomputers, will be incorporated into early intervention programming.

Involvement of parents and families will progress from the somewhat global programs of the past to individualized programming that takes into account the characteristics of the handicapped child, the individual needs of the parents, and conditions unique to the family.

Improvements in technology and understanding of family intervention will require increased levels of expertise by service providers, which will, in turn, lead to the need for high levels of training for early intervention personnel. An increasing number of colleges and universities will respond to this need for trained personnel.

Increased interest in the comparative effects of specific assessment instruments, curricula, and instructional strategies will prompt increased research into the relative effectiveness of different intervention approaches, and in cost-outcome comparisons among different approaches. These studies are likely to be better designed than past studies, and the results will tend to be more definitive than past investigations.

In the immediate future, the number and quality of early intervention programs will gradually increase, despite the lack of additional public funding. Eventually, as the number of programs increase, as the benefits of early intervention are confirmed and publicized, and as parents and others lobby in behalf of preschool handicapped children, public policy will shift toward increased legislative and fiscal support for early intervention programs, at both the federal and state level, culminating in the requirement that programs be available to all handicapped children at birth.

SUMMARY

Conceptually, the severely retarded preschooler may be differentiated from other classes of preschool-age children. In practice, the methodology for separating severely retarded preschoolers from other preschoolers is inadequate. In addition, many severely retarded children have associated disorders that permit early identification. Perhaps the most important issue in identification and diagnosis is to identify the needed components of an appropriate intervention program for the child.

During the first half of this century, severely handicapped preschoolers were kept at home or sent to institutions. A lack of optimism about the future of the severely retarded child and a lack of active programming to ameliorate the effects of the retardation existed. Since 1950, there has been a gradual increase in the number of programs for preschool handicapped children, including the severely retarded, and in leadership at the national and state level to increase services to such children. Associated training and research have increased the scope and quality of intervention, particularly through the efforts of the Handicapped Children's Early Education Program.

Unfortunately, the United States has not made a national commitment to serve all children from birth to school-age. Currently, there is no legal protection for the rights of this group, and there is no national plan for development of such legislation. Though such extension is unlikely during the current economic and political climate, it will eventually come, as professionals and society recognize the cost savings that will ultimately accrue from such a program.

The consequences of such a national program will be that an increased number of severely retarded children will be served, and families will be provided more support to enable them to keep their children at home. We will likely discover, as we did with children with Down's syndrome, that these children, too, can achieve much more than we currently think possible.

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CHAPTER 5/
EDUCATIONAL PROGRAMS FOR SEVERELY MENTALLY RETARDED ELEMENTARY-AGE CHILDREN: PROGRESS, PROBLEMS, AND SUGGESTIONS

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Historical perspectives
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Summary
References

This chapter offers an explanation of how the new field, education of the severely retarded person, began in the public school setting. The national resources that were brought to bear on the problems are described in general. The chapter is written to cover three basic areas: where the field started, the resources currently available, and finally, what to expect in the future. The reader should quickly sense that the field has made only a tentative beginning, that the elementary school years have been somewhat ignored (for reasons described later) and that there are many tasks confronting the field. A priority task, documenting the educability of this child population is outlined, and the justification for its priority status is presented. A national plan, considered critical for the survival of public education for the severely retarded student, serves as the summary for the chapter.

HISTORICAL PERSPECTIVES

An interesting group of professionals became involved in developing public school programs for severely handicapped students. Most were represented in an earlier publication of the Division on Mental Retardation (Sontag, Smith, & Certo, 1977) and many have written chapters for the present volume. Few were primarily identified as long-time teacher trainers. Instead, some were associated with single sensory handicapped research, some were psychologists (primarily applied behavior analysts) interested in fine grain research problems. Some were experts in early childhood education for the handicapped. While some were nationally known leaders in special education, others were recent graduates of programs in special education and behavioral psychology. Bearing in mind that the critical events in *PARC v. PA* (for a discussion see Laski, this volume) evolved during a crisis period during the Vietnam era, and that universities were experiencing unrest and civil disobedience, it is reasonable to consider that among those who became involved in educational programs for the severely retarded, a strong commitment to activism carried over to advocacy efforts for the severely retarded person. Though rarely addressed in the professional literature, this commitment to civil activism is a critical factor as it explains, in part, the high sense of commitment attributed to these professionals (Sailor, Wilcox, & Brown, 1980, p. ix).

Methods and Materials for the Elementary-Age Student

By the time that educational programs for the severely retarded student were initiated, it was clear that programs for the mildly and moderately retarded student held little promise as models (Cain & Levine, 1963; Guskin & Spicker, 1968; Kirk, 1964). Instead, programs drew on other resources: (a) laboratory procedures for applied research studies, (b) the systematic or direct instruction and precision teaching procedures which originated in some special education programs as early as the mid-60's, (c) the direct instruction models for early, compensatory education for the disadvantaged, (d) task analyses derived from developmental theory, (e) innovative projects for the moderately retarded, (f) intervention models for innovative infant and preschool programs, (g) growing interest in developing alternative communication systems, (h) existing state guidelines for programs for the moderately retarded, (i) curricula developed in institutional settings, and (j) behavior modification techniques.

It would be inaccurate to state that all these resources were brought to bear on this new educational problem by each of the resource personnel who contributed to these public school programs. Rather, professionals drew on those resources close at hand and central to their interests at the time. However, because this was (and is) a relatively small field, because there were federal funds to support travel for group meetings, because close working relationships existed or developed quickly, there was a climate which fostered sharing of ideas and, consequently, widespread adoption of those resources that seemed most likely to have potential for educational benefit. Thus, if one looks only at the writing of those most prominent in the education of the severely retarded student, there appears to be a common information base.

Settings

From the earliest special teacher training projects, research and development programs, and model demonstration centers—all federally funded efforts—there emerged a national resource network. For the most part, these programs were located in major institutions, where there was already a resource base for research, training, or service delivery. In many instances, teacher training programs were located at universities where there were active research and development programs. For a time, there existed a consortium of teacher trainers and state department personnel in the southeastern states, initiated to facilitate collaboration within and among states, and to supplement the resources of single training programs (SERC, 1982). This project typified the atmosphere of collaboration and exchange of ideas which stimulated the development of the field.

CURRENT PRACTICE

Theoretically, since *PARC v. PA*, all severely retarded students have the right to a public education program, and, presumably, those students attend public schools in community settings. To the extent that this is a valid assumption, it can be said that a service delivery system for severely retarded students is in place. To the extent that this is the case, a major systems development effort has been accomplished. At the *local level*, then, placements exist for severely retarded students, and a major goal of P.L. 94-142 has been met.

At the *state* level, in some instances, new certifications for teachers of the severely retarded have been developed, and there are now equivalent "program standards" for this population—whatever that may mean. In some places, Pennsylvania for example, a broad generic certification permits any teacher of special education to work with this population. In some states, e.g., Vermont, there has been a concerted effort to utilize the resources of the state and university personnel, to develop a comprehensive statewide service delivery model.

At the university level, training programs have been established on a relatively selective basis across the country. In some locales, the faculty employed to direct these programs have been in place long enough to achieve tenure and thus insure some degree of program stability. As noted, these programs often serve as centers for research and development efforts, whose outcomes or products shape the field.

Further signs of growth include *products* of developmental efforts, e.g., *Journal of the Association for the Severely Handicapped* and another for the developmentally disabled, *Analysis and Intervention in Developmental Disabilities.* A small number of method texts (e.g., Greer, Anderson, & Odle, 1982; Sailor & Guess, 1983; Snell, 1983; VanEtten, Arkell, & VanEtten, 1980; Wehman, 1979) have been published. Each contains similar instructional procedures, although the treatments range from general to specific. In addition, edited volumes such as the one by Sailor, Wilcox, and Brown (1980), have addressed a variety of specific topics.

Since the inception of the right to education movement, a *philosophy* and a *set of beliefs* has been articulated in journal articles and chapters. These have guided the development of past efforts, and will continue to shape present and future efforts. These are:

—even the most handicapped persons can learn when the instructional environment is appropriately structured

—maximum interaction with nonhandicapped persons facilitates the development of the severely retarded

—public education in community placements in neighborhood schools is necessary to meet the *least restrictive environment* provision of P.L. 94-142

—a functional curriculum directed toward semi- or totally independent living and employment skills for adulthood is an appropriate educational goal across the developmental age span

—education goals, and social integration goals should serve to normalize the life experiences of persons who, without intervention, represent one end of a continuum of human variation.

This should be considered a basic and fundamental set of assumptions. Perhaps there are others, or perhaps these might be stated differently, but it seems appropriate to view them as representative of those guiding the development of programs for severely retarded persons of all ages.

ELEMENTARY PROGRAMS

An analysis of the literature reveals little of substance that is directly referenced to elementary school programs. There are some reasons for this situation. First there was an immediate interest in developing programs for infants and preschoolers. This interest derived from existing work funded under the Handicapped Children's Early Education Program (HCEEP), and was founded on the premise that intervention from birth onward was critical to the development of handicapped children (see Gentry & Olson, this volume). Then, as these programs were established, attention shifted to the vocational years and programming for employment or community living (see Williams, et al., and Rusch, et al., this volume). Further, there was a major emphasis, reflected in the funding priorities for model programs for the severely handicapped student, to facilitate the goal of social integration of handicapped students (see Gaylord-Ross & Peck, this volume). Consequently, in the same way that psychology once defined perception as "that something that exists between sensation and cognition," the current status of elementary school programs may be described as "that something that exists between infant intervention and vocational programming."

Human variation being as diverse as it is, a teacher of 8 to 10 year old children (3rd, 4th, and 5th "grade" equivalents) must be prepared, at least in the mid-80's, to program basic response shaping (visual attending, localizing sounds, simple motor response, etc.) with some students, while others are engaged in legitimate preacademic skills such as pre-reading, 1:1 correspondence counting, and social development (game playing) with other students. One might say "But, that range typifies students who are profoundly retarded as well as high-functioning trainables or moderately retarded students." True, but if anything marks this student population it is the heterogeneity of abilities, especially as they are compounded by the presence of attendant multiple handicapping conditions. This range presents a challenge to the teacher.

Tawney and Smith (1981) suggest the existence of a number of factors which may assist the teacher in meeting this challenge:

—a theoretical base underlying existing intervention programs

—theory that translates directly into educational practice, as described by Bijou (1970)

—examples of laboratory studies designed to shape discrete behaviors utilizing reinforcement techniques

In addition, there are the basic philosophical statements listed in the previous section that may assist the teacher and program developer.

Curriculum Rationale

In the broadest terms, the goal of education is to change behavior. Parents expect students to know more at the end of the school year than they do in September. Furthermore, the classroom teacher is expected to be responsible for that change. As Tawney and Gast (in press) suggest, events have been set into motion to create an expectation that the teacher demonstrate a functional relationship between his/her intervention and child behavior change.

The task for the teacher of elementary school-age severely retarded children is essentially the same as that of the regular grade teacher—to take the child from the present level achieved by previous intervention and prepare him/her for the next level of intervention. However, the regular third grade teacher clearly knows what "end of second grade" skills are, and what is necessary for the child to enter fourth grade. The expectations for the third grade teacher are delineated as well. That is not the case for the teacher of the severely retarded student for the children she/he teaches deviate far from the norm of the regular school and there is as yet no satisfactory way to determine if the child is making "acceptable progress."

For the teacher of the 80's, it is important to realize that there are many goals inherent in the right to education movement, and that these goals may impact differently on the individual child. "Normalization," "mainstreaming," or "placement in the least restrictive environment" are broad social goals. These goals have been predominant in the attempt to obtain the placements mandated by P.L. 94-142. For the individual child, the teacher must expect to balance social and educational goals, in the same way that the regular third grade teacher is expected to present a balanced curriculum in basic academic skills. To the extent that the teacher's placement approximates the ideal—a self-contained class in a regular elementary school—the structure for social integration has been created, and the teacher's task will be to further structure social interactions that are meaningful to the severely retarded student and others in the environment.

Finally, in developing programs for the current generation of students, the teacher should recognize that, at this age level, there may be two populations. One population consists of those students who may have been institutionalized and have received little in the way of systematic intervention. Their behavioral repertoire may be very different from the student who was identified at birth, and has benefitted continuously from the exemplary infant and preschool programs described by Gentry and Olson in this text. This distinction is important because, as a profession, we have presented a stylized, or Utopian view of the life path of the person who receives, from birth through adulthood, the best that the field has to offer. However, at this point in history, only a fraction of this population may have actually benefitted from these services. And, with some degree of humility, we must admit that as yet, "our best is not nearly as good as it could be."

Curriculum Content

Given the heterogeneity of the severely retarded population, the teacher of elementary-age children should expect to draw from many resources. Since this may seem like an unrealistic expectation for the teacher, and perhaps an unmanageable scope of instruction, the following example will illustrate, and serve to document that the task is not unmanageable.

An example of one elementary curriculum has been provided by Tawney, Knapp, O'Reilly, and Pratt (1979). This curriculum was field tested over a three-year period, in four states, with approximately 300 students. The curriculum is described as teaching skills typically acquired during the first three years of life. Figure 5.1 presents an instructional profile taken from the Programmed Environments Curriculum. This profile illustrates the range of instructional objectives a teacher may expect to teach when working with school-age severely handicapped students. During the field test, this curriculum was presented to students in the first "right to education" classes; students whose functional levels ranged from profound to moderate retardation. These students also ranged from 18 months to 21 years of age. Some of these students, recently transferred from one institutional setting to another so that they could attend classes in a public school, were crib bound when not receiving instruction. Other students were older "high functioning trainables."

A student who received instruction on the programs identified in the Tawney, et al. (1979) Programmed Environments Curriculum Profile did so because he or she was pretested, failed a pretest, then became a candidate for instruction. Typically, each teacher who participated was requested to use three different programs, with at least three different children during the course of one year of intervention. Thus, children received only those programs for skills they did not possess. This is different from a typical validation of a regular reading program, where all third graders within each condition receive the same intervention. This distinction is made to emphasize that not all the participants in the Programmed Environments field validation received instruction on all programs. Rather, teachers were able to assess for, then identify appropriate individual programs for a wide

SOCIAL/LANGUAGE		COGNITIVE	PROFILE MOTOR		SELF-HELP		
Receptive	Expressive	Cognitive	Fine Motor	Gross Motor	Eating	Dressing	Grooming
		Selecting a Specified Quantity Counting Rationally Matching Equal Sets				Zipping Jacket Snapping Unbuttoning Hooking Unbuckling	Brushing Hair Brushing Teeth
		Selecting Equivalent Amounts			Eating with a Fork	Zipping Pants Unzipping Pants Untying Unhooking Putting On T-Shirt Taking Off T-Shirt	Washing Face Washing Hands
		Pairing Equal Sets				Putting On Shirt Putting On Pants Taking Off Shirt Taking Off Pants Putting Socks On	Wiping Nose
Identifying People		Sorting Lining Up Objects Putting Objects in Sequence			Eating with a Spoon	Putting Shoes On Putting Mittens On Unzipping Jacket Putting Hat On	Drying Face Using a Napkin Drying Hands
Identifying Body Parts Identifying Objects	Naming Objects Naming Actions	Identifying Simple Pictures Matching				Unsnapping Pulling Off	
Responding to Signal Words Attending to Own Name	Shaping Words Producing Sounds on Request	Imitating Actions Finding Source of Sound	Placing In/On	Walking	Drinking from a Cup		
Following Cued Commands	Indicating Preferences Responding Vocally to Model	Finding Hidden Objects Repeating Teacher Model Responding to Teacher Model	Manipulating Objects	Standing Up Crawling on Hands and Knees Standing Sitting Up Crawling on Stomach	Eating Finger Foods Chewing		
Attending to Voice Responding to Social Interaction	Making Sounds	Attending to Objects Focusing Attention	Grasping Reaching for Objects	Sitting Controlling Head Movements			

Figure 5.1 Instructional profile taken from the Programmed Environment Curriculum.

range of students. The process of assessing and then selecting from *many* available curricula or task analyses is a critical skill/task for the prospective teacher.

The content areas covered in this Profile are representative of those commonly presented in the elementary school years. At the more basic levels, content overlaps with existing curricula. Bailey, Jens, and Johnson (1983) for example, include the Tawney, et al. Programmed Environments Curriculum in comparison with 14 infant curricula in a chapter on infant curriculum development, although the curriculum authors would not necessarily consider this an infant curriculum. Similarly, task analyses of self-help skills overlap with those presented in programs for older, and higher functioning students, such as the Teaching Research Curriculum for Moderately and Severely Handicapped (Fredericks et al., 1976).

In summary, we have described the scope of curricular content, in general form, for elementary school-age severely retarded students. This clearly is an area which needs attention in the form of additional research and development of integrated curriculum approaches. We have offered an explanation for the current status of events and drawn on a representative curriculum to illustrate the range of behaviors likely to be taught. These, integrated with information from Chapters 4 and 6 should indicate to the teacher what the field has to offer in regard to curricular content.

Instructional Strategies

If the field is lacking in content descriptions, it is blessed with explicitly described instructional procedures. Tawney and Cartwright (1981) have abstracted these strategies from several sources in the literature, e.g., Snell (1983).

1. Defining what is to be taught
    a. Stating the conditions of instruction
    b. Response specification
    c. Stating criterion performance
2. Careful analysis of prerequisite skills
3. Precise behavioral assessment
4. Precise skill or content analysis
5. Fine-grain instructional sequencing—or programming for errorless learning
    a. Specification of teacher statements, cues, and prompts
    b. Specification of correction procedures
    c. Use of reinforcer systems

6. Data-based instruction—immediate decision-making based on student correct and error responses
7. Empirical verification of the effects of an educational intervention
8. Direct and daily measurement of student responses
9. Defined decision rules for program branching or program modification
10. Systematic programming through all phases of learning: acquisition, proficiency, maintenance, and generalization (Tawney & Cartwright, 1981, p. 6).

Service Delivery Personnel

The prospective teacher should expect to be assigned at least one and perhaps two full-time aides to assist in the classroom, assuming a class enrollment of 6–8 students. This number will vary, depending on state regulations. The number may be based on the degree of handicap present among class members.

The teacher should expect to recruit volunteers, e.g., age-peer tutors, high school-age volunteers, parents and foster grandparent volunteers, to increase the amount of instructional time available to students. As noted in the problems section, one topic ignored in the literature is the amount of instructional time actually available to students who are, at least in the initial stages of learning, best described as dependent learners.

Support Services

At this level, the teacher should expect to cooperate in multi-interventionist team efforts (what others may call transdisciplinary, multidisciplinary, or interdisciplinary approaches). In some settings, school policy will make the teacher ultimately responsible for supervising all the related services included on an IEP. In some settings, the teacher will be responsible for learning and implementing certain "therapeutic" techniques, while in other settings, these will be implemented outside the classroom by occupational, physical, and speech therapists.

FUTURE CONSIDERATIONS

We have articulated philosophies on the place of the severely handicapped person in society, theoretical bases (primarily behavior-analytic or Piagetian) for educational practices, strategies that directly translate theory into practice, a general concept of appropriate curriculum for the elementary school years, a clearly defined instructional technology which is useful across age levels, and models for encouraging teacher collaboration with other intervention team members. The notion of data based instruction is incorporated in our instructional technology. The prospective teacher can analyze the texts, journals, and related resources listed here and in related chapters to identify instructional sequences, skill matrices, and task analyses useful for elementary-age students. These resources form a good beginning for the content and procedures of an instructional program.

Our discussion hints at general problems in the field of education for severely handicapped (including severely retarded) persons. Further, the previous discussion identifies certain lacks in educational program development. Here, we touch on these topics, and then move on to a problem of major concern—the lack of documentation of our present efforts.

General Problems

As a profession, we may have oversold ourselves. This topic has been hotly debated (Burton & Hirshoren, 1979a, 1979b; Sontag, Certo, & Button, 1979; Tawney & Smith, 1981). See also Volume 1, Number 1 of the journal, *Analysis and Intervention in Developmental Disabilities* (1981) and the symposium in *Behavior Analysis in Education* (1984). It is not that we cannot do all the wonderful things we have said we can, it is only that we have been overly enthusiastic in our statements of belief. Critics of the right to education movement have been quick to seize on this discrepancy and have cautioned that the field may pay a price for having raised false expectations.

Closely related to this issue is another problem, individual and professional *egocentricism*. Put simply, individually and collectively, we have much less influence than we think we have. Or, perhaps it is more appropriate to say that we tend to overestimate our scope of influence. However, there is little doubt that the loose and ever changing network of training, research, and development centers has made major contributions in the last 10 years. For better or worse, we have shaped the direction of a new field. Since many of us run "nationally recognized" projects, we may tend to believe all our efforts have national impact. Undoubtedly, some do. But, in reality, most of our efforts do not impact much beyond our demonstration sites. If one accepts this premise, then it follows that our early efforts are not sufficient, and that there is much to do to create exemplary programs.

Another problem is the presumed variability that may exist in classrooms across the country. Again, graduates of the training programs, and staff of research and development centers have achieved widespread movement across the country. But, there are many reasons to be suspect about the quality of instruction which severely retarded children receive. Since the field began overnight as a result of a court order, there was an initial demand for teachers which had to be met before any of the exemplary efforts described in this text were in place. Second, teacher supply and demand factors across the country have resulted in major shifts in teaching responsibilities of those teachers in place long enough to survive layoffs. Presumably, many of these persons have been reassigned to newly emerging classes for the severely retarded student.

Future Curriculum Issues

It should be obvious that there is a need for an integrated curriculum for the elementary school years. Although the concept of training for the next, or future environment has been advanced, it remains nebulous when applied to the early school years for low-functioning students. One source of the problem is our professional view of the idealized child. That is, if we apply our most powerful interventions from birth, and thus accelerate the development of the handicapped child, our "product" should be a person who differs less significantly from the norm than do those contemporary students who have not benefitted. Thus, the next environment for preschool-age children is kindergarten, and the next environment for kindergarteners is first grade, and so on. Perhaps this will come to pass, but, in the meantime it might be appropriate to pull together instructional sequences which cut across critical content areas, e.g., in language, from shaping the aspiration of discriminably different speech sounds, to vocal imitation, speech sound production, single word utterances, appropriate use of phrases, word recognition, prereading skills, survival word skill acquisition, and so on. All of these exist, but they have not necessarily been sequenced together.

Another curriculum problem is the difference between small scale (n of 1) research studies, and widespread application of successful intervention procedures. Much of what we know now evolves from small-scale studies. In fact, much of our instructional technology, particularly that which uses a learning trial model, evolved from laboratory procedures. To the extent that these procedures are employed, and teachers find them effective, we can say that there has been successful transfer from the laboratory to the classroom. However, the studies, in and of themselves, should only be considered a starting point for full-scale testing and replication in the classroom.

The Missing Data Base

Above all else, the field lacks an empirical data base to document its effectiveness. With so much effort devoted to establishing programs, this statement seems difficult to accept. The texts, curricula, and articles listed in this chapter would seem to indicate that this educational endeavor is off to a fine start. Perhaps, but there is not adequate documentation to indicate this effort is producing significant educational change in the students being served.

As the original litigation and legislation developed, there was an implicit assumption that those severely handicapped children placed into the public education system would receive a meaningful and appropriate education. However, that is not necessarily the case. Consequently, professional and parent advocacy organizations have lobbied for changes in educational services and in one suit (*PARC v. Scanlon*, 1979), parents have charged the schools to provide meaningful, appropriate, intensive education. This situation could have been predicted, given the conditions which existed when these classes were first established. Our profession should not be surprised that those who advocated so hard for placements, now expect their children to receive the *appropriate education* guaranteed by P.L. 94-142 (see Laski, this volume). It is not unreasonable for the individual parent to ask, "Is my child learning? Show me the data." (Tawney, 1983). Or, for parents, collectively, to ask a similar question about the educational programs, procedures, and curricula we have developed in a decade. Unfortunately, as a profession, we do not yet have an adequate and positive response.

This lack has been apparent for some time. In 1980, the first author was asked to make a presentation at the 1980 national conference of the Association for Retarded Citizens. His assigned topic was to describe the academic progress of severely retarded students in public education settings. The title of the presentation became "Where is the data base on the academic performance of severely retarded students in public education settings?" To answer the question, a review of the literature was conducted. Later this review was crossvalidated by a group of students, whose reviews were again crossvalidated by the second author. For this chapter, publications from 1981 to 1983 were reviewed to bring the original paper up-to-date. This information is presented here to document the assertion that there is a limited data base. The *journals searched* were:

American Journal on Mental Deficiency (AJMD)
AAESPH Review (now JASH)
Behavior Modification
Behavior Therapy
Education and Training of the Mentally Retarded
Education and Treatment of Children
Exceptional Children
Journal of Applied Behavior Analysis (JABA)
Mental Retardation

The criteria for inclusion of the study were:

1. conducted in public school settings,
2. involved severely or profoundly retarded students (IQ under 40) of school age,

3. focused on acceleration of academic behavior, and
4. contained data.

Academic behavior was defined as any curricular content, as contrasted with traditional experimental paradigms, e.g., a two-choice discrimination problem utilizing simple stimuli.

Studies were excluded that:

1. contained the words educable or moderately retarded in the title,
2. used institutionalized populations,
3. were conducted with adults in sheltered workshop programs,
4. focused on the deceleration of inappropriate behavior, or
5. contained the words severely retarded/severely handicapped in the title but described subjects as having IQs over 40.

The review was intended to focus on studies of school-aged children enrolled in public school programs working on academic tasks: language, self-help, gross/fine motor, or concept learning. The results of the reviews are contained in Table 5.1. The reader may see several limitations of the reviews conducted. First the information presented in Table 5.1 is a journal search. It is often argued that data exist but they have not yet been published. Since three years elapsed from when the first to the last journal search was conducted, this appears not to be a major factor in the review. Second the IQ 40 may be considered overly generous, but we have erred on the conservative side, if at all. Third, studies of successful demonstrations of *deceleration* were excluded because, as noted, we wished to focus on instructional tasks, or broadly stated, those tasks likely to increase the complexity of a child's behavioral repertoire. Renzaglia and Bates (1983) have recently completed an extensive review of deceleration studies. This review is useful to the teacher who wishes to select deceleration projects. Fourth a major discriminator was the exclusion of studies conducted in institutional settings. Again, the original focus was on the public education environment.

The limited number of studies contained in Table 5.1 seems surprising. Since the first presentation of the original paper in 1980, explanations for this meager data base have included:

1. the data are there, but they are in project reports and other sources,
2. data are collected in school, but school-based studies do not survive rigorous journal review,
3. it's virtually impossible to collect large-scale data in public school settings
4. there is "personal knowledge" of program effectiveness, though it does not appear in journals, and
5. it is too soon to expect to generate program evaluation data.

Table 5.1 Studies Focused on Academic Tasks Conducted in Public School Settings on Populations of School-Age Severely/Moderately Retarded Students

Authors (by Journal)	Targeted Behavior	Subjects	Setting
AJMD			
Peterson, Austin, & Lang, 1979	Social behavior—motor-gestural and vocal—verbal responses	3	special education classes
Murphy & Doughty, 1977	Motor responses—arm pulling and arm pushing responses	7	public school
AAESPH (JASH)			
Burney, Russell, & Shores, 1977	Social behavior—vocalization, sharing, smiling	3	extramural day
Hill, Wehman, & Horst, 1982	Leisure skill—pinball play	3	public school for handicapped and community recreation facilities
Sowers, Rusch, & Hudson, 1979	Riding city bus	1	university experimental school classroom
Vogelsburg & Rusch, 1979	Crossing intersections	3	public school
Education and Training of Mentally Retarded Children			
Kauffman, Snell, & Hallahan, 1976	Imitation training	2	Experiment I, private preschool for mentally retarded children; Experiment II, special public preschool class
Gable, Hendrickson, & Strain, 1978	Social behavior—appropriate gestures, physical contact	2	public special education school
JABA			
Thompson, Iwata, & Poynter, 1979	Tongue thrust	1	public school
Mental Retardation			
Strain, 1975	Social play	8	preschool
Education and Treatment of Children			
Miles & Guvo, 1980	Disruptive and specified motor behaviors	1	school for children excluded from other public special education classes

Undoubtedly, there is some validity to each of these explanations and surely, there are other explanations. However, the fact is that the field has little to offer to respond to the individual parent, or to the critics of the right to education movement. Although some might argue that since P.L. 94-142 requires a placement and an "appropriate program," no other justification is required. We would argue otherwise.

Lacking a data base, we should develop one. The reasons are clear and compelling. In review, after 10 years, it is reasonable to request such information. The right to education movement is not without its critics, and because programs for severely retarded children differ so much from regular education, the general public can question whether they are educational at all, and thus question whether they belong in the public education system. The climate of civil rights activism which established these classes has dissipated. As responsibility for them returns completely to local control, these expensive programs are obvious targets to a citizenry with a nebulous commitment to equal educational opportunity. On one hand, critics ask not only "Can these children learn?" but also, "Is it worth the cost to teach them?" On the other hand parents' dissatisfaction has already been expressed in the 1979 continuation (*PARC v. Scanlon*) of the original civil action in *PARC v. PA* suit (1972). Thus, when critics and advocates alike ask the same basic question, "Can these children learn?", it is time to develop a plan to provide a more substantial response.

FUTURE ACTION

Foremost, it should be demonstrated to the education community, to parents, and to political supporters that low-functioning students can learn. This can be done by: (1) satisfying parents, (2) training teacher-researchers, and (3) establishing a national data base on the educability of severely mentally retarded persons.

Satisfying Parents

P.L. 94-142 contains a provision that requires parental consent to any evaluation, placement, or program initiated by the school, and then permits parents to revoke their consent at any time. It is commonly thought that parents are aware of this mechanism and their other due process rights. This assumption may be inaccurate. Indeed, in many parts of the country, it may be that the IEP is an unfamiliar document, sent home for signature, and then filed away. In order to achieve real parent approval for an IEP, it will be necessary for the individual teacher, and others in the system, to convince parents that:

1. Evaluation was carried out in accordance with all the provisions of P.L. 94-142.

2. Evaluation followed the traditional process of general and specific data collection.
3. Evaluation data are summarized with statements of strengths and weaknesses and perhaps with recommendations for learning activities.
4. There is correspondence between strength and weakness statements in the evaluation data, and the statements of present levels of performance required on the IEP.
5. The IEP contains all the educational and related services that professionals and parents have requested.
6. The IEP is actually carried out.
7. Children receive many learning trials, or opportunities, throughout the school day.
8. Children are achieving success, as they progress through sequences of learning activities.

At this level, an individual teacher may satisfy an individual set of parents that their child is receiving an appropriate education. This, however, will not sustain the field.

Training Teacher-Researchers

Tawney (1984) has proposed a model for training teacher-researchers. Briefly, the teacher-researcher can do two things well: teach students so that they achieve high and relatively error-free performance, and sequence instruction within the structure of single subject research designs. Tawney and Gast (1984) have described how to combine these efforts to conduct classroom based research. The basic goal is to encourage increasing sophistication in data collection. In essence, when today's teacher records student progress, he/she can say, "this is what Ralph learned." Teaching within the structure of a research design enables the teacher to document that a behavior change is a function of the intervention. To the extent that the teacher can provide repeated demonstrations to individual parents, he/she can satisfy them that their child is receiving an appropriate education. To the extent that whole systems adopt the teacher-researcher model (or any other that produces the same type of data), consumer satisfaction with these educational programs should increase. However, this strategy alone is insufficient to elicit continued national support.

Establishing a National Data Base on the Educability of Severely Retarded Persons

If a relatively sophisticated technology of instruction has been developed and if, as some have claimed but not yet documented, that this child population is learning in school, then, with some organization and planning, it should be possible to establish a national, collaborative research effort. To accomplish this, a national effort involving many schools at the local level, would be required.

National level. On a national level, it would be necessary to:

1. identify a core of researchers, curriculum developers, and teacher trainers, with expertise in single subject design, and with interest in child populations ranging from birth to adulthood;
2. identify a series of reasonable problems;
3. develop a funding mechanism that strengthens the resource base in potential research sites, so that teaching and research activities can be conducted simultaneously;
4. develop a management plan that insures quality control of data at individual sites, yet allows conservative use of travel monies to insure cost effectiveness;
5. develop, print, and disseminate an "intervention matrix" so that there is wide knowledge of what research is being conducted, where, and with what age groups
6. develop ahead of time, a realistic description of what this effort will and will not yield, e.g., it will yield a series of replicated demonstrations of academic intervention; it will not, on a short-term basis, yield longitudinal data on the effect of birth through adulthood intervention; and
7. develop a strategy, ahead of time, for publishing this potentially massive compendium of studies.

At the local/regional site level. At the local level, it would be necessary to:

1. identify locales (individual classrooms or school systems) where independent analysis verifies that all elements of the instructional process are in place. For research purposes, a major criteria is that a system exists for recording child performance data;
2. identify additional resource support needed to insure that data collection is carried out and that defined intervention (instructional) procedures are adhered to;
3. train teachers and local school personnel, to the extent necessary in single subject design; and
4. insure procedures for data flow from local sites to research/training centers.

Moving from this general outline of strategies to a full-scale national effort will require commitment. Still it is not an impossible task. If properly managed, the outcome (data base) should be substantial in contrast to the meager yield from nearly 10 years of model demonstration projects and 5-year institutes.

SUMMARY

This chapter began by briefly describing the history of events leading to establishing public school programs for the severely retarded student. The many resources currently available were then described and a data base on the educational progress of severely mentally retarded students in public education settings was investigated. Reasons why it is important to have a data base on the educational progress of the severely retarded students in public school settings were presented and finally, an outline for a strategy to collect a substantial data base, on a national collaborative research project was offered.

It should be clear that we believe in the potential of students generally considered severely mentally retarded. Much of the first author's work has been based on an errorless learning model and thus on the premise that even the most handicapped persons can learn at relatively error free rates, if the conditions for learning are appropriately structured. With strong empirical support, perhaps in another 10 years, more can be said about educational programming for school-age severely handicapped students. Until then, unfortunately, we can only echo what Dick Whelan (1977) said, "We've only just begun."

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CHAPTER 6/
PROGRAMS FOR SECONDARY-AGE SEVERELY HANDICAPPED YOUTH

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Major goals for secondary programs
Overall characteristics of secondary programs
Post-school environmental demands as a curriculum base
Adaptation of performance objectives
Community-based instruction
Social integration
Facilitating transitions to post-school environments
Parental involvement
Service delivery personnel
Support services
Program evaluation
Unresolved issues and challenges
Anticipated trends
Summary
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References

In reviewing the history of public school special education programs, it is evident that little attention has been paid to the design and provision of secondary services to adolescents with severe handicaps. For example, Kokaska (1968) found that in 1966 fewer than 5 percent of the school districts in the country had secondary special education programs even for students labeled "educable mentally retarded." As recently as 1972, 75 percent of all special education programs were at the elementary level (Martin, 1972). Today, it would appear that teachers of adolescents with severe handicaps enter classrooms with little assistance from research and model demonstration programs.

The relative neglect of secondary programs for students with severe mental handicaps is attributable to a number of factors:

1. Individuals with severe handicaps were thought to be unable to benefit from educational programs (e.g., Kirk, 1972), and it was believed that most would remain dependent throughout their lifetimes (Anderson, Greer, & Dietrich, 1976).
2. Until the passage of P.L. 94-142 in 1975 persons with severe handicaps were routinely denied access to the public schools through the application of minimum entry requirements which were tacitly supported by state legislation (Weintraub, Abeson, & Braddock, 1975).
3. Many individuals with severe handicaps were institutionalized prior to mandated public school services and have remained in segregated programs as adolescents, despite the recent development of many community opportunities.
4. Many persons with severe handicaps have been institutionalized at the onset of adolescence which has contributed to a disproportionately low secondary enrollment. This low enrollment has in turn resulted in lack of comprehensive public school expertise with severe handicaps at the secondary level.
5. Until recently federal policy and funding priorities have unintentionally contributed to the pattern of neglect by not focusing on the development of appropriate curricula, service delivery models and teacher competencies for secondary level programs for individuals with severe handicaps (e.g., Thompson, Wilcox & York, 1980).

Despite this bleak history, there are indications that increased attention is now being directed toward the educational needs of adolescents with severe mental handicaps. With the continued State and Federal commitment to deinstitutionalization and the direct provision of services by local education agencies, secondary-age students with severe handicaps are beginning to attend public schools in local communities throughout the country. The practical needs of these students and the programs providing services to them are attracting the attention of professionals and commanding an increasing portion of local and Federal resources.

MAJOR GOALS FOR SECONDARY PROGRAMS

The educational integration of learners with severe handicaps reflects an increasing trend to include these individuals in the mainstream of society (Novak & Heal, 1980). The major philosophical impetus of community integration is embodied in the principle of normalization, which stresses the delivery of services in environments and under circumstances that are as culturally normal as possible (Nirje, 1969; Wolfensberger, 1972). Recent interpretation of this principle includes expanding programs for persons with severe handicaps to encompass the broad array of services and activities available to most residents of a community (Rusch & Schutz, 1981). In the near future the majority of individuals with severe handicaps should receive educational, recreational, domestic living, vocational, and general community living services in community-based settings rather than in large institutional or segregated settings (Brown, Branston, Hamre-Nietupski, Johnson, Wilcox, & Gruenewald, 1979).

The philosophical impetus of community integration has been accompanied by impressive applications of instructional technology which has resulted in individuals with severe handicaps acquiring complex community living skills. Some of the community living skills that have been taught to persons with severe handicaps include:

—Skills to perform relatively complex tasks in sheltered work settings (e.g., Bellamy, Horner, & Innman, 1977; O'Neill & Bellamy, 1978);

—Skills to acquire and maintain competitive employment (Wehman, 1981; Wehman & Hill, 1980);

—General domestic living skills such as cooking, ironing, housecleaning, safety, telephone use, grocery shopping, clothing selection and money (Sailor & Guess, 1983; Snell, 1983);

—General community living skills such as time management, bus riding, street crossing and restaurant use (e.g., Sailor & Guess, 1983; Snell, 1983); and

—Community recreation leisure skills such as games, sports, hobbies (e.g., Wehman & Schleien, 1980).

The philosophical change regarding the locus of services for individuals with severe handicaps has far-reaching implications for public schools. To facilitate the success of individuals with severe handicaps in integrated community settings, it is essential that they be provided with opportunities to learn functional skills to help them participate independently in a variety of settings (Schutz, Vogelsburg & Rusch, 1980). It is equally important that both handicapped and nonhandicapped individuals be provided with skills and longitudinal experiences to socially interact in integrated community environments (Brown et al., 1979). The task of preparing severely handicapped persons to function adaptively in community-based settings is becoming the responsibility of local public school systems (Schutz, Williams, Iverson, & Duncan, 1984).

In order to prepare learners with severe handicaps for adult life in the community, secondary level programs must be future oriented. Secondary-age learners with severe handicaps have only a few remaining years in public school and educational programs should focus on preparing them to function in post-school environments (Brown et al., 1979; Wilcox & Bellamy, 1982). Parents and educators must carefully consider what the possible post-school residential, vocational, recreational/leisure and educational environments will be for individual learners. In addition, most learners with severe handicaps will require continued services and support throughout their post-school years. Educators and parents must identify post-school service providers and develop a plan for facilitating learners' access to necessary services (Brown, Pumpian, Baumgart, VanDeventer, Ford, Nisbet, Schroeder & Gruenewald, 1981).

Selection of post-school work, living and educational environments plus support service options should be determined through *value negotiation, service availability* and *anticipated learner performance level*. Value negotiation recognizes that parents, educators and significant others often have different expectations concerning post-school living, working, and educational environments and support service needs. For example, parents may expect the learner to live at home and attend a work activity center, while professionals may expect the learner to live in a group home, work part time and attend an adult education program to receive further training on independent living skills. Selecting the environments for which learners will be prepared and specific skills which they will be taught should be included as part of the IEP process with parents, educators and significant others, jointly accommodating their values in the decision making process (Brown et al., 1979; Wilcox & Bellamy, 1982).

The educator's role in selecting post-school environments and addressing post-school support service needs should be one of providing information to parents and significant others on the options and process for accessing available options. To perform this role, the educator needs to be knowledgable about post-school living and working environments plus agencies which can meet post-school support service needs (Sailor & Guess, 1983).

Some communities have extensive post-school support services for severely handicapped learners such as case management, adult education, vocational training, sheltered work, group homes and supervised apartments. However, even when such services exist, there are often waiting lists and performance criterion for learners to access the services (Vogelsburg, Williams & Friedl, 1980). Parents and educators need to work closely with agencies which provide post-school services in order to get learners on waiting lists plus identify and train skills which will facilitate access to services.

Although there may currently be insufficient post-school living and working environments or the environments available may be less than satisfactory, programming should not be restricted to existing resources (Wilcox & Bellamy, 1982). Preparing severely handicapped individuals for current opportunities in the adult service system may result in them participating in environments which are institutional, segregated and custodial in nature. This is counter to the intent to prepare individuals with severe handicaps to participate in integrated independence-oriented community work and living environments. Post-school opportunities for individuals with severe handicaps are emerging and current post-school options do not necessarily reflect those which will be available in the near future (See Brinker, this volume). Educators and parents should work with adult service agencies to advocate for increased access to community living alternatives and nontrivial work (Vogelsburg, Williams & Bellamy, 1982).

Secondary level special education programs for severely handicapped learners should have three major goals:

1. Prevention of institutionalization;
2. Preparation for participation in future work, independent living and educational environments; and
3. Transition of learners into integrated and least restrictive post-school environments and service delivery systems.

OVERALL CHARACTERISTICS OF SECONDARY PROGRAMS

To identify characteristics of a comprehensive secondary program, the emerging literature on secondary programs was reviewed for learners with severe handicaps. Table 6.1 contains selected characteristics and related literature. The information in Table 6.1 is not intended to be exhaustive in identifying all the characteristics of a secondary program or delineating all related literature.

It is not the intent of this chapter to review all the characteristics indicated in Table 6.1. Many of the characteristics such as classroom schedules, IEPs, age appropriate placement, systematic data collection, integrated therapy, and instruction on skills through functional activities should be characteristics of programs for students of all ages and are addressed in other chapters. Rather, this chapter focuses on those characteristics with particular relevance for secondary populations which include educational objective selection based upon performance demands of post-school environments; adapting performance objectives; community based instruction; social integration; planned transitions to post-school environments and services; and parental involvement.

Post-School Environmental Demands as a Curriculum Base

The recent emergence and recognition of the need to provide more appropriate secondary programs for learners with severe handicaps has resulted in educators closely examining the basis for secondary level curricula. An increasing number of curricula experts are advocating that the demands of adult-life or post-school environments should form the basis of curricula at the secondary level (e.g., Brown, et al., 1979; Brown, Nietupski, Hamre-Nietupski, 1976; Sailor & Guess, 1983; Wilcox & Bellamy, 1982). Basing

Table 6.1 Characteristics of Secondary Level Programs

Characteristic	Related Literature
Age Appropriate Placement, Curriculum, and Materials	Wehman & Hill, 1980; Wilcox & Bellamy, 1982
Parental Involvement in IEP Development	Brown, Certo, Belmore, & Crowner, 1976; Wehman & Hill, 1980; Wilcox & Bellamy, 1982
Performance Requirements of Post-School Environments Utilized for Objective Selection	Brown, Branston-McClean, Baumgart, Vincent, Falvey, & Schroeder, 1979; Wilcox & Bellamy, 1982
Planned Transitions to Post-School Environments and Services	Brown, Wilcox, Sontag, Vincent, Dodd, & Gruenewald, 1977; Sailor & Guess, 1983; Wilcox & Bellamy, 1982
Community Based Instruction in Natural Environments	Brown, Certo, Belmore, & Crowner, 1976; Wehman & Hill, 1980; Wilcox & Bellamy, 1982
Instruction of Skills through Functional Activities in the Natural Environment	Brown, Falvey, Baumgart, Pumpian, Schroeder, & Gruenewald, 1980; Wehman & Hill, 1980; Wilcox & Bellamy, 1982
Planned and Regular Interactions with the Nonhandicapped	Brown, Branston, Hamre-Nietupski, Johnson, Wilcox, & Gruenewald, 1979
Specific IEP Objectives for each Learner	Wehman & Hill, 1980; Wilcox & Bellamy, 1982
Structured Classroom Schedule that Indicates Student Activities Throughout the Day	Wehman & Hill, 1980; Wilcox & Bellamy, 1982
Systematic Direct Instruction	Sailor, Wilcox, & Brown, 1980; Sailor & Guess, 1983; Wilcox & Bellamy, 1982
Systematic Data Collection	Sailor, Wilcox, & Brown, 1980; Sailor & Guess, 1983.

curricula content on the performance demands of post-school environments involves the use of an ecological inventory strategy (Brown, et al., 1979; Wilcox & Bellamy, 1982). This strategy identifies actual post-school work independent living and recreational/leisure environments to which learners could potentially have access. After the environments have been identified, the educator surveys the environments to determine performance requirements and the identified performance requirements become a basis for the curriculum (See Rusch, Chadsey, White & Gifford, this volume).

Various authors have developed different steps and varying procedures for generating curricular content based upon an ecological inventory approach (e.g., Brown et al. 1979; Vogelsburg et al., 1982; Wilcox & Bellamy, 1982). The steps may be accomplished in a slightly different order and strategies for completing the steps may vary. However, the basic steps and procedures delineated below provide a basic framework for deriving specific curricular content for individual learners with severe handicaps.

1. *Delineate potential post-school work, recreation, living and educational environments and service options.*
2. *Interview parents/guardians to delineate priority post-school environments and service options.*
3. *Determine performance requirements of specific post-school environments and procedures for accessing services.*
4. *Use performance requirements of post-school environments as the basis for assessing learners and delineating possible curriculum and IEP objectives.*
5. *Perform other relevant assessments to insure that all relevant skills are considered.*
6. *Through the IEP process and consultation with parents/guardians and support staff, finalize specific post-school environment objectives for individual learners.*
7. *Develop and implement strategies for transitioning learners to post-school environments.*

The procedure for developing curricular content should be a process which begins with selecting objectives generally useful across a variety of post-school environments and culminates in training skills for specific post-school environments. For the fifteen- or sixteen-year-old entering a secondary level program for the first time, training may be provided on work and independent living skills identified across a variety of post-school work and independent living environments. When a learner has one or two years left in school, training may be provided on the skills for the specific post-school environments in which the learner is expected to be placed.

The strategy of initially providing training on skills needed across environments followed by training for specific environments is advantageous. It is typically not appropriate and often not possible to select the specific post-school environments for fifteen- to-sixteen-year old learners with severe handicaps. However, potential environments can be selected.

Based on information generated from providing training on skills needed across potential environments, more realistic decisions on appropriate placements can be made as learners approach leaving school. For example, in the area of vocational training, learners may initially be provided with experiences and training on a number of different jobs through in-school and community-based training. Depending on learner preference, parent preference, learner performance, and availability of jobs in the community, the learner may be trained on a specific job which could result in post-school employment. Learners with severe handicaps should not be arbitrarily targeted for restrictive environments such as sheltered work and group homes. Training should be based on preparing them for the least restrictive environment such as competitive employment and supervised apartments. Only after training data indicates that competitive employment or a supervised apartment is not a practical reality, should more restrictive environments be given serious consideration.

The content of secondary level curricula should focus on reducing individual dependencies on others and enhancing the quality of environments to which learners have access. The content should be individualized and should significantly vary from learner to learner. Depending on individual learner need content can include: Teaching mobility (e.g., walking, wheelchair use) and direction following skills which allow more participation in community activities such as shopping and recreation/leisure under supervision; teaching independent street crossing and bus riding; teaching independence at home or in a group home; teaching skills which will facilitate placement in a supervised apartment; teaching independence and productivity in a sheltered workshop; and teaching competitive employment skills. Even learners with the most severe handicaps can be taught skills which decrease dependence such as partial participation in self-care recreational (e.g., use of a joy stick to turn on a record player), and domestic living activities.

Adaptation of Performance Objectives

Severely handicapped learners should be allowed to participate in community activities even if they cannot engage in the activity independently. Adapting performance objectives to allow for partial participation assures that learners have the opportunity and are taught, to participate in activities as independently as possible.

As delineated by Brown, Branston-McClean, Baumgart, Vincent, Falvey and Schroeder (1979) adapting performance objectives to allow for partial participation can be facilitated through providing personal assistance and/or adapting activities, sequences and rules. Personal assistance involves providing assistance on only those elements of an activity the learner cannot perform. For instance, if a learner can select food items and pay a cashier but cannot carry a food tray, someone could carry the tray to allow the learner to participate in the other activities.

Adapting activities involves changing the activity to allow for more independence or complete independence. An example is making waffles. If the waffles are made from a mix, the learner may need assistance in measuring out the ingredients. However, if toaster waffles and a toaster are provided, the learner may be able to acquire the skills to complete the activity more independently or with complete independence.

Adapting skill sequences involves changing the sequence in which skills are performed. As an example, purchasing food in a fast food restaurant typically involves the following sequence of skills: waiting in line, placing an order, taking money out of the wallet, paying the cashier, and taking the food to a table. A learner who has difficulty taking out a wallet and securing money from it may perform these skills at a rate which is not acceptable to either the cashier or other customers waiting in line. To alleviate this problem, the learner could be taught to take out the wallet and money while waiting in line to accommodate the rate problem.

Adapting rules includes changing the rules of activities so the individual can participate in them. Examples include changing the distance between stakes in a game of horseshoes, lowering the net in volleyball, and giving points for hitting the volleyball rather than requiring that the ball travel across the net.

There are two basic strategies which can be employed to increase independent participation in community activities. One, the skills involved in the activity can be identified and learners can be taught to perform them. Two, the activities can be adapted so that performance of some complex skills are not required (White, 1980). Many skills encompassed by community activities are difficult to teach or take a long time to learn. For example, counting out the correct amount of money, telling time, reading menus, verbally placing an order for merchandise, planning a menu and generating a shopping list are skills that many severely handicapped learners can acquire. However, they are often difficult to teach and typically require significant instructional time. Many secondary-age severely handicapped learners may not have adequate time in school to make teaching such skills a practical reality. When skills are translated into functions, it is often possible to devise alternative ways learners can carry out the functions. Examples of skills, the function of the skill, and functional alternatives are described below.

Skill	*Function*	*Alternative*
Counting out the correct amount of money when making a purchase	Providing the clerk with an amount of money equal to or greater than the purchase	Give a dollar amount more than the purchase price. (If an item is $1.62 give $2.00.)
Reading the restaurant menu and verbally giving an order	Select and order food items	Picture menu to order food by pointing to the picture
Walking	Mobility through space	Wheelchair, crutches
Talking	Communication	Sign language, Communication board
Brushing teeth	Oral hygiene	Use a water pic, electric toothbrush

It must be emphasized that teaching learners functional alternatives does not rule out teaching them to perform the functions as typically performed by nonhandicapped individuals. For example, learners could be taught to use a communication board while they were concurrently learning to speak.

Community-Based Instruction

Three primary concerns in selecting instructional strategies for secondary level learners with severe handicaps encompass selecting strategies which: Enhance skill acquisition; insure skill performance under conditions and performance criteria of post-school community environments; and facilitate skill generalization (Brown et al., 1976; Brown et al., 1979; Falvey, Brown, Lyon, Baumgart & Schroeder, 1980; Wilcox, & Bellamy, 1982; Williams, Brown & Certo, 1975). Strategies which have been employed include in-school simulations and community-based instruction (Wilcox & Bellamy, 1982). Each approach has advantages and disadvantages which should be carefully considered when selecting a strategy or combination of strategies for individual learners with severe handicaps.

In school simulated instruction refers to training under conditions which approximate the natural environment, but which does not occur in the natural environment. Training learners to use a mock-up grocery shop, cross a pretend street, or assemble widgets on an assembly line in school are examples of simulated instruction. A major advantage of classroom instruction is that the environment can be highly structured to minimize distractions and to provide for systematic instruction.

Although simulated instruction has distinct advantages, it has several significant disadvantages which dictate that it be used in combination with other approaches. A major disadvantage is that it does not train skill performance under the conditions and criteria that exist in post-school work and independent living settings. Skill maintenance and generalization in the environments where skills are ultimately to be performed are not addressed. A second disadvantage is that certain skills cannot readily be taught in the simulated setting. Appropriately communicating with a nonhandicapped store clerk, interacting with a fellow customer at a restaurant, transversing an icy sidewalk, getting on and off the bus at appropriate locations, and appropriately interacting with nonhandicapped co-workers are examples of skills that cannot be easily trained through simulated instruction.

Despite the fact that simulated instruction has been used to teach a variety of skills such as street crossing (e.g., Neff, Iwata, & Page, 1978; Page, Iwata & Neef, 1976), and telephone use (e.g., Nietupski & Williams, 1974), there is no empirical evidence that learners with severe handicaps will generalize skills to the natural environment or that it is more efficacious than other strategies such as community-based training (Falvey et al., 1980; Coon, Vogelsburg & Williams, 1981; Wilcox & Bellamy, 1982).

Community-based training refers to teaching skills under conditions which exist in the natural environment. It has been used to teach such skills as grocery shopping (Nietupski, Certo, Pumpian & Belmore, 1976); bus riding on city buses (Coon, et al., 1981); street crossing on actual streets (Vogelsburg & Rusch, 1979); and work skills used in community sites (Wehman, 1981). Community-based training has the following advantages:

1. It does not assume that learners will generalize and maintain skills taught in simulated settings to natural environments. It teaches skills under conditions and criteria which exist in natural settings.
2. It ensures the clusters of related skills are taught instead of focusing on isolated skills. For example, teaching grocery shopping through community-based training could involve instruction on such skill clusters as dressing for the weather, getting to the store (e.g., bus riding and/or cross streets), problem solving (e.g., what to do when items on a grocery list are not available), and interacting with nonhandicapped fellow shoppers. Simulated instruction typically isolates specific skills (e.g., locating grocery items and purchasing) and does not attend to the numerous skill clusters which are encompassed by the task.
3. When community-based training is provided in an individual learner's specific post-school work and independent living environment, it is more likely that the learner will be able to perform and maintain the skills in those environments.

Disadvantages of community-based instruction are primarily logistical and administrative (Brown, et al., 1979; Vogelsburg, et al., 1982). Factors which have been delineated as inhibitors of community-based instruction include: Additional transportation; scheduling community training and teacher coverage; liability questions, and safety. Implementation of community-based training disrupts the status quo and must be carefully planned. An additional disadvantage of community-based training is that some skills may be more efficiently taught prior to generalizing them to the natural environment. Such skills as discriminating among coins, recognizing bus routes, or discriminating between food items on a prosthetic shopping aide (e.g., picture board of food items) may be more efficiently taught through such procedures as match-to-sample in the classroom before teaching in the community.

Simulated instruction should attempt to teach skills under conditions and criteria that approximate the natural environment. Based upon the task being taught and individual learner needs, some combination of simulated and community-based instruction should be employed to take advantage of the strengths of each approach. Ultimately, community-based training should be provided for work and independent living tasks to ensure performance in natural environments.

Social Integration

An integral component of programs for secondary level students with severe handicaps should be social integration. To facilitate participation in integrated community environments nonhandicapped individuals in those environments should attain knowledge and experiences from social interaction with persons with severe handicaps. Furthermore, individuals with severe handicaps should attain skills and experience by interacting with nonhandicapped persons.

Nonhandicapped people typically have little knowledge and experience in interacting with individuals with severe handicaps. This lack of knowledge and experience can result in misconceptions about handicapping conditions which may inhibit interactions. In addition, they are usually unsure of how to interact or communicate with persons who may be nonverbal, have limited speech, and/or communicate through gesture, signs and communication aids.

Special educators should systematically plan activities which will provide nonhandicapped persons with knowledge and experience in interacting with individuals with severe handicaps. This may be accomplished in the school setting through developing and implementing an in-school social interaction plan. As delineated by Iverson, Williams, Schutz and Fox (1983) an in-school social interaction plan can be developed by a team of special and regular educators. These educators can develop social interaction strategies appropriate for their school. Strategies can include such activities as presentations by students and staff on disabilities, integration into ongoing school activities, and inclusion of an unit on handicaps and integration in the school curriculum. Experiences interacting with individuals with severe handicaps can consist of such activities as lunch, gym and extra curricular activities while facilitating interactions during the activities. In addition, nonhandicapped students can be recruited to be peer tutors and buddies who teach students with severe handicaps specific skills and facilitate partial participation in integration activities.

Community-based training can be a vehicle for providing the general community with knowledge and experience in interacting with people with severe handicaps. When conducting community based training, special educators should function as trainer advocates. A trainer advocate trains individuals with severe handicaps in integrated community settings and provides nonhandicapped individuals in the setting with information which should facilitate appropriate interactions. For example, when teaching learners with severe handicaps to grocery shop, the trainer advocate should inform the shop clerk about the program and offer to answer any questions.

If such functional alternatives as pictorial shopping aids are employed, relevant store employees may be provided information on the aid. Relevant store employees may also be instructed on how to communicate with nonverbal learners. It is important to emphasize to clerks that students are learning to perform the tasks independently and that they should try not to provide unnecessary assistance. In addition, trainer advocates may arrange to make presentations at various business groups to inform the general community about the program.

Students with severe handicaps can be taught a variety of skills to facilitate social interactions in integrated community settings. The skills taught should encompass grooming, hygiene, dressing skills and acceptable physical mannerisms such as appropriate posture, gait, looking at people when interacting, and appropriate facial expressions (Hamre-Neitupski, Ford, Williams, & Gruenewald, 1978). Additional skills include initiating interactions, responding to interactions, sustaining interactions, and terminating interactions (Hamre-Nietupski et al., 1978). Students should acquire and practice such skills throughout daily living activities.

While improvement in the interactive behavior and social skills of students with severe handicaps is imperative and can be accomplished, it may not be possible in all instances for these individuals to become highly competent in these skills and socially astute (Guralnick, 1978; Stainback & Stainback, 1982). However, if these students were excluded from integration activities and experiences until they have demonstrated acceptable levels of social skills, they may never have an opportunity to participate. A logical alternative is train nonhandicapped persons to interact with severely handicapped students who may exhibit "different" behavior in social situations.

Facilitating Transitions to Post-School Environments

To facilitate access to post-school environments and services, planning for transitions to these environments and services should begin when learners enter the secondary level program. The procedures for developing a transition plan overlap with the procedures for delineating adult environment demands. In developing a transition plan, the educator should go beyond identifying environments and skills necessary for access to environments and become directly involved with post-school service providers in planning a smooth transition from school to post-services. Transition planning may be accomplished in the following steps:

1. *Delineate Post-School Vocational, Recreational, Domestic and Educational Environments and Service Options.* Important considerations in transition planning are overall case management and identification of agencies which can provide follow-up and training after learners leave school.

2. *Contact Service Providers.* Adult service providers should be contacted early so that they can begin to plan for services and develop procedures for coordinating school and post-school services.
3. *Meet with Adult Service Providers on a Regular Basis.* Adult service providers should be contacted on at least a yearly basis to update the procedures for transitioning individual learners to adult services. During the learners' last years in school, more frequent contacts will be needed to complete the transition.

Transition planning is a zeroing in process with the focus moving from general to specific performance demands based upon the age of an individual learner.

Parental Involvement

Parents or guardians should have significant involvement in the development and monitoring of educational programs for secondary level students with severe handicaps. During the students' secondary program crucial decisions are made regarding post-school services and vocational, recreational, domestic and educational options. The educator should provide parents with information on post-school services and environmental options. The educator should also provide parents with support and assistance in investigating and selecting various post-school services and environmental options.

Parents and educators should work as a team in selecting post-school services and environments, developing an individualized educational program which will facilitate students' accessing and participating as independently as possible in the environments. Accomplishing these tasks requires extensive ongoing parent and teacher communication. On at least an annual basis parents and teachers should meet to discuss and delineate post-school service options and environments, articulate strategies for transitioning students into the services and environments, and prioritize educational objectives which should be included in IEPs to facilitate access to the services and environments. Meetings should take place prior to formulating students' IEPs to guarantee that relevant objectives are included.

In addition, parents and teachers should develop an ongoing communication plan. The plan should consist of parents and teachers delineating what types of information they need to share on a regular basis, how often they need to communicate (e.g., daily, weekly) and the best vehicle for communicating (e.g., note, telephone calls, conferences). The plan should be individualized on the basis of specific student, parent and teacher needs. The goal of the plan should be to enhance the parent and teacher working relationship, to share information and accomplishments in transition planning, and to facilitate consistency for the learner.

SERVICE DELIVERY PERSONNEL

Provision of appropriate programs for secondary-age learners with severe handicaps often requires reallocating instructional resources, redefining educator's roles, and teaching educators additional knowledge and performance competencies. Selected knowledge and performance competencies include: Community-based training; developing plans to transition learners from school to post-school environments; working with multiple agencies in preparation of transition plans; working with parents and others in selecting high priority objectives which facilitate transitions and in selecting post-school environments and services; conducting ecological analyses; securing community training sites for work and independent living training; and scheduling the day and instructional resources to allow for community-based work and independent living training. Typically, teacher preparation programs do not focus on such knowledge development resulting in few special educators being adequately prepared to provide state-of-the-art secondary level education services for learners with severe handicaps.

New roles for secondary level special educators are being created through the emphasis on teaching to post-school work and independent living environments. Some school systems have reallocated teachers making them vocational trainers or general community trainers. The vocational and community trainer take responsibility for developing community work and independent training sites conducting community training and coordinating community instruction with classroom instruction. The classroom teacher provides teaching which is referenced to community-based training activities. As secondary-level programs emerge and are evaluated, service delivery personnel needs and roles will be more fully articulated.

SUPPORT SERVICES

Secondary level learners with severe handicaps need the same basic support services as middle and elementary-age learners. Based upon individual learner needs, such support services as occupational therapy, physical therapy, speech/language therapy, and adaptive physical education should be provided. However, support service personnel can take on different roles when working with secondary-level programs. The speech/language therapist can provide assistance in the identification of communication systems and content needed in post-school environments and help the teacher translate the needs into ongoing instructional programs. Physical and occupational therapists can design adaptations for community environments.

Adaptive physical educators may provide recreation/leisure training in community environments as part of the physical education program.

Many learners with severe handicaps will need support services in their post-school years. Within the transition process, support service providers can identify post-school service needs, help identify post-school support service providers and work with them on facilitating a smooth transition between school and post-school support services.

PROGRAM EVALUATION

Secondary level programs for learners with severe handicaps can be evaluated in terms of what state-of-the-art practices are in place and program outcomes. A simple checklist may be used to determine if state-of-the-art practices are in place. A sample checklist similar to the one depicted in Table 6.2 may be employed. Note not all best practices are depicted in the sampe checklist. Such a checklist can be used by educators and administrators in program development. Those components not in place can be identified and necessary actions to institute them can be taken.

The most important evaluation is output evaluation. This evaluation is concerned with whether or not a program is achieving its objectives and if the program is benefitting the learners. As in Table 6.2 a column which notes the percentage of learners involved in each best practice can be added

Table 6.2 State-of-the-art Evaluation Checklist

	In Place		Actions Required		Percent of Students Involved
Practice	Yes	No	Yes	No	
1. Age Appropriate Activities					
2. Parental Involvement to Develop High Priority Post-School Environments					
3. Ecological Analyses Used for Curriculum Base					
4. Transition Process in Place					
5. Regularly Scheduled Vocational Training					
6. Regularly Scheduled Community Based Training					

Table 6.3 Sample Post-School Follow-Up List

PERCENT OF STUDENTS TRANSITIONED TO	0–25	26–50	51–75	76–100
Vocational Training				
Independence Training				
Percent Living in Natural Homes				
Foster Home				
Group Home				
Supervised Apartments				

PERCENT OF STUDENTS WORKING	0–25	26–50	51–75	76–100
No Work				
Sheltered Work				
Supervised Employment				
Volunteer Work				
Part-Time Work				
Full-Time Work				

to the chart. These data can be used to document an increase in the percentage of learners participating in each practice over a period of years.

Traditionally, educational programs have evaluated effectiveness in terms of how many skills learners acquired while in a program. Increases in learner performance are interpreted to mean that learners benefitted from the program. However, increased skill performance does not necessarily yield information on participation in integrated post-school work and independent living environments. A list similar to the one depicted in Table 6.3 may be used to partially evaluate this. Data derived from Table 6.3 can be used to indicate the percentage of students who enter various vocational and residential settings. Knowledge of these percentages may provide indications for program development or revision. Whether or not learners access such environments may be due to factors outside of a program's control such as availability of supervised apartments, vocational training and slots in sheltered workshop programs. The information may be used to identify a need to work with adult service providers on the development of more options.

UNRESOLVED ISSUES AND CHALLENGES

Provision of secondary level special education programs for learners with severe handicaps is a new frontier in special education. Although some school systems have begun to develop exemplary service delivery systems for secondary-age learners, such school systems are islands of excellence. There has not been widespread implementation of best practice in secondary programming and few projects have developed replicable and validated models for delivering services. In addition, there is little research which addresses issues faced by service providers developing and implementing secondary level programs.

The challenges faced in the provision of secondary programs are due largely to lack of appropriate service delivery systems. Service delivery systems at the local level will have to be changed to acommodate serving learners in chronologically age-appropriate integrated settings, basing curriculum on the demands of adult life, providing community-based training, planning transitions to adult services, and working cooperatively with post-school service providers. The solutions to these challenges must be found at the local levels since such factors as: Expertise of existing staff; barriers to change; work, recreation, and independent living opportunities; availability and quality of adult services; and funding patterns will vary from community to community. Specific system change strategies which may work in one community may be ineffective in another (Thurman & Fiorelli, 1979).

To address the challenges involved in providing secondary programs, demonstration projects are needed to develop, evaluate and disseminate system change strategies. Models for providing exemplary services should be validated and disseminated. Personnel preparation programs which prepare teachers and support staff to provide secondary services should be emphasized. In addition, there is a need for research which addresses curricula, instructional procedures, program organization, and other issues confronting the practitioner providing direct services at the secondary level.

ANTICIPATED TRENDS

Although there may be temporary setbacks and substantial challenges along the way, it is anticipated that policy emphasis on deinstitutionalization and prevention of institutionalization will continue. The continued trend towards providing services in the community should produce an emphasis on secondary and adult programs which have resulting cost benefits. The

Parent Advocacy groups, professionals and other concerned citizens who worked to obtain a free appropriate public education for learners with severe handicaps have already begun to focus on encouraging appropriate service delivery systems at the secondary and post-school levels. Changing secondary level and adult service delivery systems to provide appropriate and effective services will not occur overnight. A long term concentrated effort will be required to meet the challenge.

SUMMARY

In summary, there is an emerging literature which indicates that the technology to enhance the independent functioning of learners with severe handicaps in community work and independent living environments is available. Learners with severe handicaps represent an extremely heterogenous population and increases in independence have ranged from learners acquiring the complex skills to use buses, restaurants and grocery stores independently, to acquiring basic skills which allow them to partially participate in independent living activities. The challenge now faced in provision of secondary level programs is developing and implementing effective service delivery systems which facilitate increased independence in post-school environments. Service delivery systems must be changed to enable the application of available instructional technology to produce increased independence in post-school community environments.

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CHAPTER 7/
PROGRAMS FOR SEVERELY MENTALLY RETARDED ADULTS: PERSPECTIVES AND METHODOLOGIES

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History of adult programs (1950–present)
Forming cohesive networks: The ecobehavioral perspective
Engineering an ecological balance: A new curriculum focus
    Focus of treatment
    Intervention effects
Developing standards for evaluating programs: A new instructional strategy focus
Important issues surrounding the establishment of adult programs
    Interagency collaboration: Coordination of services
    Expanding the boundaries of a special education: Developing adult personnel preparation programs
Summary
Reference Notes
References

Throughout history, societies have established customs, laws, and moral codes that determine "normative" behavior. These norms set the standards by which individuals are judged. Frequently, mentally retarded adults, like other community members, display behaviors that do not "fit" community expectations, and consequently are either ostracized or perhaps worse, ignored. Traditionally, the mental health profession, with primary responsibility for serving severely mentally retarded adults, has opted to exclude this population from mainstream community activities. Prevalent public opinion often forces the extraction of the "problem person" from the community to segregated residential and adult "day care" settings

Our perspective challenges this practice by introducing a definition of community integration—the focus of this chapter—that stresses the need for the systematic study of settings so that severely mentally retarded adults can recreate, live, and work together with nonhandicapped persons. From our perspective:

> *Community integration refers to the process of uniting handicapped and nonhandicapped individuals as equal members jointly participating in recreational, residential, and employment settings. An integrated community is a cohesive network of people and resources, which is linked together by common expectations and shared interests. Cohesive networks are formed when individual differences are accepted and individual growth and development is enhanced by recreational, residential, and employment coordination.*

This chapter builds upon this definition by describing perspectives and methodologies that enhance services for the severely mentally retarded adult. First, a selective review of the history of programming for severely mentally retarded adults is presented. Next, the "ecobehavioral approach" is introduced from which an overarching framework for the study of community integration is developed and, finally, this chapter presents methods that should be incorporated to guide service providers with primary responsibility for developing adult programs for severely mentally retarded individuals. The primary methodology, referred to as social validation, incorporates the opinion of a community by requesting the community to evaluate the practical value of the individual's habilitation goals and to evaluate the results of habilitation efforts in attaining these goals. This methodology, even in its current early state of development, is critical to successful community integration of severely mentally retarded adults. Standards for evaluating programs are discussed next, followed by other unresolved issues and problems associated with adult programs.

History of Adult Programs (1950–present)

Formal and informal social processes influence whether individuals are united as equal members jointly participating in recreational, residential, and employment settings. Historically, systems-level problems (such as the existence of individuals who can not participate in employment programs due to ineffectual rehabilitation education programs) have resulted in social policies that specify conditions whereby these problems are reduced or eliminated. Since 1950, formal public policies enacted by Congress have dramatically influenced the lives of severely mentally retarded adults, both positively and negatively (see Noel, Burke & Valdivieso, this volume). *On the positive side,* the Vocational Rehabilitation Amendments of 1954 authorized grants to nonprofit agencies in support of research and development of employment options for mentally retarded persons. Between 1954 and 1964, as many as 150 grants were awarded to establish sheltered workshops preparing mentally retarded adults for employment. Prior to 1954 there were only six sheltered workshops in the United States, located in San Francisco, New York City, Tampa, Denver, Minneapolis, and Newark (Nelson, 1971).

In 1961, President John F. Kennedy established the President's Committee on Mental Retardation, which recommended a national plan to eliminate systems-level problems related to mentally retarded individuals' quality of life. Shortly thereafter, Congressional action led to the development of community-based mental health centers (P.L. 88-164 and P.L. 89-105), which were additionally funded by vocational rehabilitation and mental retardation amendments (P.L. 89-333 and P.L. 90-170). These actions resulted in the construction and staffing of community-based residential facilities. Once these facilities were established a most significant legislative act evolved in that federally-subsidized income maintenance programs for mentally retarded individuals were begun. In 1971, Title XIX of the Social Security Act (P.L. 92-323) provided Medicaid money for individuals residing in community-based facilities who were designated "medically needy." Congressional action also resulted in the Social Security Amendments of 1972 (P.L. 92-603), known as the Supplementary Security Income program (Title XX), which provided income maintenance to low income, mentally retarded individuals. The net result of this legislation was funding for community-based residential facilities, including attendant care, medical services, and funds for personal needs.

On the negative side, these funds continue to be, paradoxically, only available to individuals who have been labelled "inconsequential producers." In essence, if it can be demonstrated that persons are capable of productive work through demonstration of social or vocational competence they become ineligible for Title XX and consequently for Title XIX funds. Thus, some formal policies established by the federal government, although well meaning, have reinforced the idea that severely mentally retarded adults are inconsequential producers. Further, the 1966 amendments to the Fair Labor Standard Act authorized establishing work activities centers serving individuals not considered capable of benefitting from existing sheltered workshop programs (Neff, 1970).

There are other negative consequences. The subtle and cumulative result of our history of social reform has led to the recognition of goals conflicting with contemporary ideology and methodology that supports our community integration approach. For example, the "dual role" of the sheltered workshop is becoming widely recognized. Neff (1970) distinguished between the "rehabilitation workshop" and the "sheltered workshop" with the former functioning as a transitional service for competitive employment, and the latter as providing remunerative employment to those who were considered incapable of employment apart from supervision.

Employment and residential training, similar to educational programs (Reynolds, 1962), has been based upon an ideal continuum of services. In the context of employment this continuum typically ranges from "day care" to competitive employment. Unfortunately, this continuum does not operate well in communities because coordination does not exist for advancing adults from dependence upon publicly-supported programs, to reliance upon integrated community services and products (Rusch, 1981). Because federal legislation has been naive to programming integration, the decade of the 1980s began with as many as 20,000 mentally retarded adults referred to segregated and sheltered employment programs each year (Whitehead, 1981). Similarly, since 1960, approximately 4,000 segregated and sheltered community residential facilities have been established within the United States (Heal, Novak, Sigelman, & Switzky, 1980).

At least 30 federal programs influencing severely mentally retarded adults' lives, achieved primarily through social advocacy, exist. These programs involve the means for providing recreational, residential, and employment opportunities. Today, it is apparent that some of these policies either have outlived their usefulness or have resulted in negative side-effects not anticipated. For example, although many severely mentally retarded adults have benefitted from competitive employment training, the number of these adults currently participating in the American workforce is low. This, in part, is attributable to the fact that social reforms have led to service delivery only in segregated and sheltered facilities. Specifically, entitlement programs (e.g., Title XIX, Title XX) assume that severely mentally retarded individuals cannot benefit from traditional services or even extended sheltered employment opportunities offered in sheltered workshop programs. Consequently, work activity programs exist. Governing rules and regulations for work activity programs require that individuals, to be eligible for income maintenance (SSI), be incapable of productive employment. Inability to work also qualifies these individuals for the Title XIX Medicaid program. To illustrate, any adult capable of productive employment not only loses SSI eligibility but within one year must learn to recreate and live independently. Since many unanswered questions remain regarding the strategies to ensure successful integration, the government should now take steps to answer these questions by providing those same monies to service providers and researchers that actively promote and study community integration, rather than providing monies to those that discourage this process. Society should not allow severely mentally retarded adults to be caught in a "catch 22." Federal programs should support the education of adults so that they can recreate, live, and work independently in a community.

Forming Cohesive Networks: The Ecobehavioral Perspective

One important and recent contribution to social science has been the formation of the ecobehavioral perspective (Rogers-Warren & Warren, 1977;

Chadsey-Rusch, 1985; Willems, 1977). This perspective has application for recreational, residential, and employment programming for severely mentally retarded adults. The ecobehavioral perspective to community integration incorporates principles and methods borrowed from behavioral and ecological psychology. Behavioral psychology, in particular the behavior analytic approach (Baer, Wolf, & Risely, 1968), has been used successfully to teach a variety of community integration skills, including mobility skills (Matson, 1980; Sowers, Rusch, & Hudson, 1979; Spears, Rusch, [illegible]rk, & Lilly, 1981; Vogelsburg & Rusch, 1979), self care (Horner & Keilitz, 1975; Martin, Rusch, James, Decker, & Trtol, 1982; Nutter & Reid, 1978), social skills (Bates, 1980; Garcia, 1974; Matson, 1978; Matson & Martin, 1979; Mithaug & Wolf, 1976; Snell, 1979), money management (Bellamy & Buttars, 1975), telephone use (Smith & Meyers, 1979), leisure activities (Wehman, Berry, Karan, Renzaglia, & Schutz, 1978), and vocational skills (Bellamy, Inman, & Schwarz, 1978; Bellamy, Peterson, & Close, 1975; Close, Irvin, Prehm, & Taylor, 1978; Connis & Rusch, 1981; Irvin, 1976; Irvin & Bellamy, 1977; Matson & Martin, 1979; Mithaug, 1981; Wehman, Schutz, Renzaglia, & Karan, 1977). Although the behavioral approach has proven useful for teaching valued behaviors and changing behaviors, the approach proposes little regarding *which* community integration behaviors to teach (Rusch & Mithaug, 1985) and frequently views behavior from too narrow a perspective (Willems, 1974). Ecological psychology, with its focus upon the study of individuals within the physical and social milieu, presents a means to study natural communities from a systems approach. Ecological psychology is well documented in the literature (Auerswald, 1969; Barker, 1968; Brunswick, 1955; Lewin, 1951; Schoggen, 1978), and has become a "buzz-word" in the field of mental retardation (c.f., Brooks & Baumeister, 1977; Berkson & Romer, 1980; Bruininks, 1982; Haywood, Meyers, & Switzky, 1982; Rusch & Mithaug, 1985; Schalock, 1985; Schalock, Karan, & Harper, 1980; Scott, 1980). Ecological psychology emphasizes the study of interdependencies occurring between people, behaviors, and settings in natural contexts. This perspective acknowledges that any change in the "environmental system" will result in interdependent changes throughout that system. For example, changes in one system, such as employment, may result in changes in another system, such as ineligibility for medicaid payments.

The concept of setting or context is central to ecological theory, and may prove to be central to successful community integration efforts. For Barker (1968), behavior and setting are interdependent and particular patterns of behavior are reliably associated with particular physical and social contexts. For example, an individual is likely to display a different set of behaviors while attending church (e.g., praying) versus while attending a baseball game (e.g., cheering), yet different individuals will display similar behaviors in both settings. Although behavioral continuity exists across settings, behavior is influenced by the setting and in turn influences the setting. In the church setting as well as in the ball park individuals are influenced by their setting as well as contribute to it.

Moos (1973) expanded upon the concept of ecological interdependencies in delineating methodology for classifying behavior in relation to setting characteristics by the use of behavior-setting "matrices" (Barker, 1968). Utilizing behavior-setting matrices, Moos suggested five dimensions for the classification of setting characteristics: (a) ecological dimensions (e.g., geographical, architectural); (b) dimensions of organizational structure (e.g., staffing ratios, salary levels); (c) personal and behavioral dimensions descriptive of setting inhabitants (e.g., age, ability level, socioeconomic status); (d) dimensions related to psychosocial characteristics and organizational characteristics (e.g., role patterns, authority structure, social norms, rules); and (e) dimensions related to functional environmental analyses (e.g., reinforcing properties, discriminative stimuli). These dimensions, singly and in concert, are useful in identifying a typography of human behavior.

In the field of mental retardation, Berkson and his colleagues (Berkson, 1981; Berkson & Romer, 1980; Heller, Berkson, & Romer, 1981; Melstrom, 1982; Romer & Berkson, 1980a; 1980b; Romer & Berkson, 1981) have provided insightful examples of the use of ecological methods to study relationships among mentally retarded adults in segregated and sheltered facilities. Traditionally, ecologists seek to minimize disruptions in ongoing streams of events, a consideration particularly salient to the integration of severely mentally retarded adults into communities. Berkson's program of research directed attention toward ecological relationships, describing relationships between persons and settings, which would promote the formation of cohesive networks involving persons and settings. The marriage between behavioral and ecological perspectives would combine proven behavior-change strategies with a molar "systems-level" conception of human behavior.

Community integration is a complex undertaking. When considering severely mentally retarded adults and the settings they should frequent, interdependencies between persons and setting must be carefully assessed and sometimes, altered. If harmony is apparent and ecological balance exists, then person-setting relationships need not be modified. If discord is present, these relationships must be changed by either altering persons or settings through behavioral strategies or prostheses (Schalock, 1985). Whenever changes are made, however, their interdependent "reverberations" must be monitored across the system linking persons, behaviors, and social and physical environments (Willems & Stuart, 1980). Community integration is a dynamic process accounting for individual changes and reverberations in formal (e.g., government) and informal (e.g., friends, family) social systems. If a defining characteristic of an integrated community is the presence of a cohesive network of persons and resources linked together by community expectations and interests, then engineering ecological balance must be central to the goal of community integration.

Engineering an Ecological Balance: A New Curriculum Focus

Cohesive networks are formed by linking common expectations and shared interests. In contrast to biological ecology, the ecobehavioral perspective capitalizes upon the unique capacity of human language and communication. Humans can be consulted to provide information regarding the acceptability accompanying systemic changes that occur when previously segregated individuals are introduced into the community. A major advance in how to utilize opinions to gauge expectations of behavior that leads to the formation of a cohesive community has been the introduction of social validation methodology (Kazdin, 1977; Kazdin & Matson, 1981; VanHouten, 1979; Wolf, 1978).

Social validation refers to a methodology that accounts for the social context of treatment in evaluating community expectations and satisfaction (Wolf, 1978). Social validation has two components, the focus of treatment and intervention effects. Social validation of the *focus of treatment* pertains to whether a behavior selected for treatment is important in enhancing the target individual's everyday functioning, i.e., facilitates successful community placement. Social validation of *intervention effect* examines acceptability of the magnitude of behavior change.

Social validation should be the primary method of choice for determining the curricular focus for severely mentally retarded adults. Social validation combines the basic needs of target individuals and the expectations of advocates, family members, and other significant persons in developing curricular and intervention priorities. Risley (1970) suggested that both criteria (i.e., needs and expectations) are essential to validating program intent and effect. The focus upon basic needs provides a standard for establishing interventions that are necessary for individual growth. The essential question asked is whether behavioral programs result in the target person acquiring a skill that improves everyday functioning. Presently, most curricular approaches for adults focus upon the basic needs required to live in residential settings in the community. Traditionally, these skills or needs have been selected based upon their functional value and have been task analyzed into instructional components. Table 7.1 illustrates an analysis by Schalock (1981) of various, traditional independent living and community skills curricula.

Besides basic needs, curricula content should also be based upon the expectations of others. Social criteria, based upon expectations, require that these programs or curricula are clinically important for the individual and valued by society. Social validation extends beyond examination of more traditional skills training as the criterion for acceptability because it identifies therapeutic criteria by experimental means (e.g., by quantification). Clinical significance, for example, is difficult to establish unless significant others (e.g., community members) or clients themselves determine "acceptable behavior." Social validation ensures that intervention

Table 7.1 Independent Living/Community Living Curriculum Analysis[1]

Title	Format[a]		Functional Level[b]	Setting	Content-Behavioral Skill Areas[c]								
	A	T			PH	SCS	FM	SB	C	HLS	FA	RL	CAU
An Activities of Daily Living Curriculum for Handicapped Adults (Tiller, 1978)		×	Moderate	Group Home	×	×	×	×	×	×	×		×
Becoming Independent: A Living Skills (Westaway & Apollini, 1978)	×	×	Moderate	Group Homes/ Apartment	×	×	×	×	×	×	×	×	×
Community Living Skills: Assessment and Training (Conroy, 1978)	×	×	Unavailable	Group Homes/ Apartment	×	×		×		×			×
Community Living Skills Screening Test and Remediation Manual (Schalock & Gadwood, 1980)	×	×	Mild to Severe	All living facilities	×	×	×	×	×	×	×	×	×
Home and Family Living Laboratory (Tramp, 1979)	×		Mild/Mod.	Independent Housing				×		×	×	×	×
Independent Living Behavior Checklist (Walls, Zane, & Thuedt, 1979)	×		Mild to Severe	Group Homes/ Apartment		×	×	×	×	×	×		×
Independent Living Skills Curriculum (Taylor, Close, Carlson, & Larrabee, 1981)	×	×	Mild/Mod.	Group Homes	×		×			×	×		
Skills to Achieve Independent Living (No author, 1975)	×	×	Mild/Mod.	Group Homes/ Apartment	×	×	×	×	×	×	×	×	×
Social Perceptual Training Kit for Community Living for Trainable and Educable Retarded Citizens (No author, 1978)	×	×	Mild/Mod.	School			×	×	×	×	×	×	×
The Individual Assessment and Program Guide (Fisher, 1976)	×		Moderate	Group Homes	×	×	×	×	×	×	×	×	×
Toward Independent Living (Baker, Brightman, & Hinchaw, 1980)	×	×	Special needs children	Natural home	×	×			×		×		
Training for Independent Living (White, 1975)		×	Mild/Mod.	Apt. (P.M.)	×		×	×	×	×	×		×

[a] A = assessment; T = Training

[b] Functional level as stated in material

[c] Behavioral Skill Abbreviations: PH = personal hygiene; SCS = self care skills; FM = food management; SB = social behavior; C = communication; HLS = home living skills; FA = functional academics (time and money); RL = recreation and leisure; CAU = community awareness and utilization.

[1] Adapted from Schalock, R. Independent living material. *Community Services Forum*, 1981, 1, n.p.

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priorities (i.e., focus of treatment and intervention effect) are not arbitrarily or stipulatively circumscribed.

Social validation methodology is important to our efforts to integrate adults, and is in part a product of recent legal decisions and of attitudinal and philosophical changes toward the developmentally disabled. These legal decisions have included the establishment of equal rights for mentally retarded persons in a normal environment (e.g., Wyatt vs. Stickney, Public Law 94-142). These rulings suggest that severely mentally retarded individuals have a right to education in typical surroundings.

Attitudinal and philosophical changes have been the result of concern for the Scandinavian principle of normalization (Nirje, 1970; Wolfensberger, 1972). Normalization suggests the use of procedures that are as culturally normative as possible for developing behaviors that are as culturally normative as possible. Despite these changes, however, normalization and community integration are ideals possible only so far as severely mentally retarded adults achieve community acceptance. The normalization approach should not be allowed wholesale proliferation without consideration of the implications for a mentally retarded person's quality of life. The "normalization backlash" is recognized because available research suggests mainstreaming may frequently lead to rejection and ostracization of mentally retarded persons by community members (Novak, 1980).

Normalization is based upon the belief that people must learn skills that enhance community acceptance. That is, the focus and effectiveness of behavior change efforts must be of sufficient magnitude to be valued (or at least noticeable) to community members. Social validation, as a method for examining the social acceptability of goals and results, is a response to the fact that perception of severely mentally retarded adults is at the crux of community integration (Briton, 1979).

Two procedures to evaluate the social validity of goals and results are social comparison and subjective evaluation. The method of social comparison involves examination of a target individual's behavior before and after habilitation with similar behavior of nonhandicapped peers. Social validation is demonstrated when, after treatment, target behavior is as valued as that of nonhandicapped peers. With the method of subjective evaluation, target behavior is evaluated by experts or significant others with whom the client has contact (e.g., friends, neighbors, coworkers), in order to demonstrate that change resulting from habilitation is perceived as important.

Social validation of treatment focus has obvious importance for community integration. Behavior has social implications and typically influences social acceptability. Successful community integration requires that the severely mentally retarded adult display a variety of valued behaviors, for example, mobility skills, domestic skills, self care, money management, time management, and telephone skills. Equally obvious is the need to eliminate gross behavioral deficits or excesses, including forms of bizarre or self-destructive behavior. However, behavior problems vary across individuals and settings, and should, therefore, be identified at the local level for the individual case. Social validation helps to identify an individual's problem as a way to remove obstacles to successful integration.

Focus of Treatment The method of *social comparison* identifies the requisites for normal community living. Nutter and Reid (1978), for example, used social comparison in teaching five institutionalized, severely mentally retarded women how to select their clothing to coincide with popular fashion. Appearance is important for community participation and acceptance. These women were taught to select color-coordinated clothing in accordance with popular fashion based upon local norms. Normative data were obtained through *direct observation* of over 600 nonhandicapped women in the local community. Typical combinations of clothing and the garments worn, were recorded. Observations were taken in a variety of settings such as a local shopping mall, a sidewalk, and a restaurant. Multifaceted training, including modeling, instruction, practice, praise, and feedback, was successful in teaching the skill of selecting popular color-coordinated clothing. Moreover, although training began with a puzzle with which the target women combined or interchanged clothes, a follow-up from 7 to 14 weeks later indicated that popular dressing skills generalized and maintained with their actual clothing.

Subjective evaluations are similarly useful when identifying the focus of treatment. *Opinions* are solicited from persons capable of making meaningful decisions about a client's behavior due to their exposure to the client or their professional expertise. Mithaug and his colleagues used subjective evaluation to identify the skills required for entry into sheltered workshops (Johnson & Mithaug, 1978; Mithaug & Hagmeier, 1978). Administrative and supervisory personnel were consulted to ascertain their priorities for job placement programming. These data proved useful for developing a conceptual framework to guide training for job placement in the community. Ten steps were identified for prevocational training, including surveying potential community job placements, assessing skills required for placement, and evaluating students with respect to these requirements. The use of subjective evaluation led to the identification of several student characteristics required for entrance into sheltered workshops, including personal hygiene, productivity, and social interaction.

Intervention Effects After training priorities are identified, social validation methodology can be used in curriculum development. Social validation is valuable in evaluating intervention effects and in ascertaining their magnitude by determining whether a client's everyday functioning has been enhanced. As with identification of treatment focus, the evaluation of intervention effects is achieved primarily through social comparison and subjective evaluation. In evaluating the effectiveness of interventions, social comparison of client's behavior with that of nonhandicapped peers is conducted to determine whether the client's and the nonhandicapped peers' behavior are similarly valued. Azrin and Armstrong (1973) used social comparison data to verify the effectiveness of a training program designed to teach appropriate eating. Severely mentally retarded residents of a state institutional ward, when eating, were reported to use inappropriate utensils, throw and spill food, steal food from others, and eat food previously spilled on the floor. A multifaceted training program, incorporating reinforcement, manual guidance, positive practice, and other techniques proved useful in eliminating these inappropriate eating behaviors and in developing appropriate eating behaviors relative to baseline for each subject, and in comparison to a control group of residents receiving routine staff-supervised training. Normative data for social comparison were collected on ward staff eating behavior. These normative data indicated that residents' eating behavior after training was indistinguishable from that of institution staff.

As subjective evaluations are of value in determining the focus of treatment, they are also useful in determining whether treatment is of sufficient magnitude to alter community members' perceptions of clients. Rusch et al. (1980) utilized subjective evaluation to assess the training effectiveness of a program designed to reduce topic repetition of a moderately mentally retarded individual employed in a nonsheltered, competitive employment setting. Rusch et al. (1980) consulted supervisors and coworkers in this setting to ascertain troublesome behavior that required change. Supervisors and coworkers indicated that one worker repeated topics excessively during conversations. Consequently, these coworkers were provided preinstruction on how to use instruction, feedback, and mild social censure as a consequence when this worker repeated a topic. During the intervention, direct measures obtained by trained observers showed that the intervention was effective in markedly reducing repetitions. However, coworkers indicated they believed that topical repeats had not been reduced in contradiction to direct measures. Thus, it appeared that treatment effects were not sufficiently large to influence coworkers' ratings.

Social validation of intervention programs is clearly important to the successful integration of severely mentally retarded adults into our communities. Subjective evaluations and social comparisons are necessary for incorporating community members as "collaborators" in behavior change leading to community integration. Not only can their opinions be referenced with respect to shared interests and expectations, but sometimes significant others can be involved directly in behavior-change efforts.

Developing Standards for Evaluating Programs: A New Instructional Strategy Focus

Traditionally, adult programs emphasize the acquisition of skills needed for survival in settings. Examples of such skills include the ability to cross streets at corners (Vogelsburg, 1979), or prepare meals in apartments (Martin et al., 1982). For these skills to have value, however, they must endure beyond the presence of supervision. Recently, the need for a technology for the promotion and maintenance of skills has been acknowledged by Gifford, Rusch, Martin, and White (in press). These authors made explicit the goal of behavioral independence by identifying two components of independence: autonomy and adaptability. *Autonomy* refers to the ability to perform learned skills with minimal supervision (Rusch, 1979). *Adaptability* refers to the ability to perform survival skills across settings. The concept of *settings* is viewed in a broad fashion to include not only physical settings (e.g., grocery store, apartment) but also refers to the interaction between persons and behaviors occurring within those physical settings. Figure 7.1 displays hypothetical profiles characterizing persons along the dimensions of autonomy and adaptability. Bob is able to remain on task with minimal supervision and to perform these skills in alternate settings. Ted remains on task without supervision, but has difficulty transferring this ability to other settings. Martha cannot perform a skill independently, although provided supervision she can transfer her skills to novel settings. Finally, Sarah is unable to remain on task without supervision, regardless of setting.

Studies exemplifying autonomy and/or adaptability exist. For example, in an effort to promote autonomy, Martin (1982) trained individuals in preparing meals at home by using pre-instruction, instructional feedback, and picture cues. Following acquisition of target skills, a partial withdrawal of each training component was undertaken. Specifically, one component was withdrawn at a time with the effects of the withdrawal assessed. Once the intervention was shown to be effective in maintaining the meal preparation skills the intervention was withdrawn from a second and finally a third individual. In Martin's (1983) study, partial withdrawal of training components resulted in the maintenance of the acquired meal preparation

AUTONOMY	ADAPTABILITY: Minimal	ADAPTABILITY: Maximal
Maximal	TED Remains on task without supervision; transfers to new setting with difficulty	BOB Remains on task without supervision; transfers to new setting easily
Minimal	SARAH Remains on task only with supervision; transfers to new setting with difficulty	MARTHA Remains on task only with supervision; transfers to new setting easily

Figure 7.1 Hypothetical profiles along the dimensions of autonomy and adaptability.

skills for each individual in the study, indicating that each of these individuals did not require supervision in the performance of the target skills.

A recreational study by Hill, Wehman, and Horst (1982) illustrates a strategy promoting adaptability. In this investigation, a 15-year-old severely mentally retarded, nonverbal male was taught how to play an electronic pinball machine in sheltered and nonsheltered community settings. It was believed that training in multiple settings would enhance the likelihood of skill transfer across settings. Hill et al. (1982) found that the multiple-setting teaching strategy resulted in superior performance in the community. Similarly, Horner and McDonald (1982) addressed adaptability by investigating the ability to bend and cut electronic capacitors to fit a template. Single instance instruction and general case instruction were compared. Specifically, the experimental design involved subjects receiving baseline assessment and single instance training followed by general case instruction. In each phase, probe sessions were conducted using 20 capacitors on which students received no instructions. Results indicated that general case instruction was superior to single instance training for prompting performance across nontrained examples. These results suggest the value of developing adaptability strategies that promote behavior across settings.

Another study embodying both autonomy and adaptability training was conducted by Wacker and Berg (1983). Five severely mentally retarded adolescents were taught two complex assembly and packaging tasks utilizing pictures as cues. Modeling, verbal correction, and contingent praise were combined with picture representations of the tasks. Selective withdrawal of training components was subsequently initiated; testing on novel tasks was conducted simultaneously. Results indicated that the training components successfully promoted acquisition, the sequential withdrawal procedure facilitated autonomy (maintenance), and general case instruction (Becker & Englemann, 1978) resulted in adaptability or generalization of skills.

Although acquisition of skills will continue to require further study, service providers and researchers must also evaluate programs along the dimensions of autonomy and adaptability. If the goal is community integration, then it is important that severely mentally retarded adults be as independent as possible. Further reading on the instructional strategies used in this area can be found in Gifford et al. (in press).

Important Issues Surrounding the Establishment of Adult Programs

Although the "best practices" concerning curricular and instructional strategies will continue to be important issues in the area of adult programs, other issues are likely to be debated. Two problems in particular concern the need for: (a) a network of inter-related services that are coordinated; and (b) personnel preparation programs that prepare professionals to adequately meet the habilitation needs of severely mentally retarded adults.

Interagency Collaboration: Coordination of Services A variety of social service systems, such as those relating to health, welfare, and rehabilitation, provide support for severely mentally retarded adults (Schalock, 1985). Because severely mentally retarded persons by definition have multiple handicaps, no one service delivery system adequately serves their needs. Consequently, services provided by community agencies, specific to each of these needs, are required. As money available to service systems continues to decrease, and public concern for the issues of accountability and cost-effectiveness increases, it becomes apparent that community services must work together. Recent federal legislation (e.g., Section 503 and Section 504 of the Rehabilitation Act of 1973; P.L. 94-142, the Education for all Handicapped Children Act of 1975; and P.L. 94-482, Title II of the Education Amendments of 1976) provide the impetus for social system collaboration.

"Collaboration should be viewed as a process through which two or more agencies work together to combine their separate programs for the purpose of providing special educational and related services to handicapped learners and their families" (Johnson, McLaughlin, & Christensen, 1982, p. 396). Baxter (1982) has argued that cooperation between agencies is an effective way to combine or maximize resources. Collaboration has been used to increase referrals, make available trained staff, equipment, or facilities, and to provide alternative or novel delivery programs. Historically, both special education and vocational rehabilitation have successfully used interagency agreements to benefit clients as well as themselves (Baxter, 1982).

Interagency collaboration is implied within our definition of community integration and fits comfortably within the ecobehavioral framework. Since community integration refers to joint participation in recreational, residential, and employment settings, it implies that all community residents, mentally retarded and nonhandicapped, use the same service systems to meet their needs. The use of such "generic services" has been strongly advocated elsewhere (Gollay, Freedman, Wyngaarden, & Kurtz, 1978; Savage, Novak, & Heal, 1980; Schalock, 1985). Although interagency collaboration does not specifically refer to the use of generic services for mentally retarded individuals, its philosophical emphasis on combining existing resources, rather than creating new specialized resources, makes the use of generic services a logical component of the interagency collaboration model.

Interagency collaboration is also essential to the ecobehavioral approach in community integration. As previously stated, an ecobehavioral approach implies a broader view of human behavior. That is, service providers must consider that any behavior change within one system (e.g., employment) will probably effect behavior change in other systems (e.g., residential, health care). Imagine the negative consequences that would result if school teachers did not collaborate with community employers in identifying adequate skills for employment, but rather relied solely upon commercially-available curricula that emphasized the acquisition of skills potentially irrelevant to community interests and expectations. Or, imagine a physician prescribing psychotropic medication at such a high dose that it interfered with acquisition of vocational skills. For ecobehavioral success, it is essential that different agencies serving the individual, as well as service providers within the same agency, coordinate efforts and realize their reciprocal impact.

Although interagency collaboration is desirable, it is also difficult to achieve. As Martinson (1982) has pointed out, most agencies strive for independence and specialization rather than for collaboration. Although numerous barriers to interagency collaboration exist (Johnson et al., 1982; McNelly, 1980), the most salient barrier is inappropriate and ineffective communication between personnel in service systems (Johnson et al., 1982). Thus, one training priority is to improve interpersonal or interagency communication. This same priority has been identified as important for interdisciplinary cooperation within service systems. In summary, interagency collaboration must be considered a vital part of effective service delivery to severely mentally retarded adults.

Expanding the Boundaries of a Special Education: Developing Adult Personnel Preparation Programs The deinstitutionalization movement has been in full swing since the introduction of the principle of normalization (Wolfensberger, 1972). Unfortunately, perspectives (such as normalization) and methodologies (such as interagency collaboration) have been misconstrued by service providers associated with adult programs. For example, normalization has been misconstrued to mean that community placement, alone, will automatically benefit the deinstitutionalized individual. Simple exposure to the "patterns and conditions of everyday life which are as close as possible to the norms and patterns of mainstream society" (Nirje, 1969, p. 181) has not guaranteed acquisition and maintenance of community competencies associated with successful community integration. Community integration involves much more than the physical removal of an individual from one setting and his/her placement into another. "Geographical relocation" is but one of the characteristics of community integration (see Butterfield, this volume). Indeed, relocation and forming a cohesive network of people and resources is complex and personnel who are trained to appreciate these complexities are needed. However, few university programs exist that certify special education personnel specifically to work with mentally retarded adults.

Many service providers in the field now will require inservice training to update their skills to successfully integrate severely mentally retarded adults into community settings (Sailor, 1983). Those professionals working with severely mentally retarded adults, particularly in institutions, in large intermediate care facilities, and in sheltered workshops, have generally not been as successful in implementing integration efforts as their peers working with mentally retarded children in public school settings. Again, this may in part be explained by the lack of university programs certifying special education personnel to work with severely mentally retarded adults.

As with interagency coordination problems, there also remains the problem of coordination between different disciplines. For example, few speech pathology, physical therapy, or social work programs emphasize work with severely mentally retarded adults and few programs emphasize the need for cooperation between disciplines. This problem has also plagued public school programs (Bricker & Campbell, 1980).

In summary, the two issues of interagency collaboration and personnel preparation should be considered problem areas that deserve further study in order to discover potential solutions. These two issues seem particularly important in the face of diminishing resources and accountability.

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SECTION FOUR/ CRITICAL ISSUES

CHAPTER 8/
PARENTS/FAMILIES OF PERSONS WITH SEVERE MENTAL RETARDATION

BUD FREDERICKS

Teaching Research

The impact on parents and family
Parents and professionals
Successful parental involvement
Issues and concerns
Summary
Reference Notes
References

This chapter presents a discussion of the effects of a severely mentally retarded family member on the family. The chapter also focuses on issues and concerns which parents and professionals perceive regarding the care of people with severe mental retardation and parental involvement with programs that serve such people. It provides descriptions of successful parent/family involvement in such programs. Finally, anticipated trends for parental involvement are discussed.

The Impact on Parents and Family

The birth of a child is an important event in any family. The typical American middle class perception of a birth is one of high expectations by the mother and the father. This is a familiar portrait that is displayed on television and in most magazine articles. Yet we all know that a birth of a child for many families can be difficult, causing family economic difficulties and psychological stress in one or more of the parents if the child has been unplanned or unwanted. Thus, to generalize about parental reactions to the birth of a child with severe mental retardation is exactly that—a generalization. And yet, there are some common reactions which can be verified by those of us who have experienced them and by skilled professional observers. There is general agreement that most parents, when told that their child is severely mentally retarded, exhibit shock, disbelief, occasionally a refusal to accept the diagnosis, and usually a reaction against the professional who has told them about the problem. Many writers have discussed these various reactions and generally agree that one or more of the above characteristics is likely to occur when the parent is first told about the birth of a handicapped child (Love, 1970; Menolascino, 1974).

Some writers have indicated that there are different stages through which a parent goes. For instance, Baum (1962) discussed the stages of: 1) parental grief, 2) denial of abnormality, 3) parental hostility, 4) guilt and shame, and 5) withdrawal. Menolascino (1974) suggests similar stages.

Some parents may feel many of the emotions listed by Baum (1962), but our experience in the Parent Training Network of Oregon has indicated that if, in fact, these stages do generally exist, there seems to be a changing trend today. Parents still experience shock, disbelief, and extreme concern. They are sad and unhappy. That sadness does not quickly dissipate; it lasts for quite awhile and may, as the child encounters various other situations through his life—teasing by his peers, failure to succeed in certain activities, failure to be accepted by others—re-emerge. That sadness is for the child and comes from wanting him/her to be accepted by others. But initially we see, even among parents who are still exhibiting severe grief and concern, a trend to an earlier search for assistance and help. We see parents with six-week-old Down syndrome children approaching professionals, asking for help and asking what they can do to become involved in active programs to help their child progress as normally as he or she can. Brazelton (1982) had a similar reaction: "It has constantly surprised us that, even in the face of a devastating diagnosis of retardation, a parent can have the energy available to search for and work with the more hopeful, positive behaviors of the baby. For example, parents of babies with Down syndrome can work to achieve an interactive alert state in the baby, and, within this state, they can teach the afflicted infant to achieve remarkable developmental steps" (p. 11).

We believe that this current trend to seek earlier help from professionals may be a function of the greater availability of services and the awareness that physicians and others have of such services. What we do not know, however, is whether this trend to seek earlier help means a lessening of the length of the stages described by Baum (1962) and Menolascino (1974) or some alteration of their sequence. Research is needed to determine if better services mean changing patterns of acceptance.

If our perception of an increased ability of parents to rebound from the initial shock of being made aware of a retarded child is correct, this factor needs to loom large in the consideration of the types of services that should be provided for families of young children with severe mental retardation. Burden (1980) demonstrated that the depression that parents of handicapped infants exhibited prior to beginning a period of home teaching decreased significantly during a two-year period in which mothers of 20 children were engaged in such teaching.

What are the long range effects of the impact of having a severely retarded child? Perhaps Vincent, Laten, Salisbury, Brown and Baumgart (1980) summed up a major consideration when they stated that families of handicapped children should be able to experience the same ups and downs that families of normal children do, e.g., frustration, joy, questioning, and predicting. The major point that needs to be remembered is that these families are first of all families. They have all the needs that families have, as well as some unique needs because of their handicapped child. Cleveland and Miller (1977) found that most families had adequate personal resources to cope with the problems of having a retarded child and also were able to provide an environment for the proper development of their normal children. Geist and Baer (1980) reported that mothers in the Chicago area who had handicapped children were able to pursue their outside interests. A study by Gallagher, Cross and Scharfman (1981) indicated that families who were successful with their handicapped children resembled families who were effective with their nonhandicapped children and seemed to be able to place the problem of having a handicapped child in perspective along with other needs of the family unit.

Thus, parents of children with retardation do experience grief and sadness, but the evidence seems to indicate that most well adjusted families can also adjust to having a family member who is retarded. Moreover, adjustment occurs more rapidly if parents are provided some tools, not only to cope with the child, but also to teach the child to cope.

A major gap in the research literature is the lack of studies that focus on the effect of a severely retarded family member on siblings. Research is being undertaken in this area by both the Early Childhood Research Institutes and the Severely Handicapped Research Institutes, but to date no published studies have been located.

Parents and Professionals

One of the major factors that seems to influence initial parental reactions to a child with severe mental retardation is the manner in which the information is passed to the parents by the professional who makes the diagnosis. In most cases parents are informed that they have a severely handicapped child by their physician. Odle, Greer and Anderson (1976) indicate that physicians should be more skilled in empathetic methods of communicating. Puescel and Murphy (1977) analyzed from the responses on written questionnaires 414 parents' perceptions of their experiences at the birth of their children with Down syndrome and came up with some basic principles that should be followed: (1) Both parents should be present when the doctor informs them of the condition; (2) appropriate terminology should be employed with tact and truthfulness; (3) kindness and sensitivity are essential; and (4) unconditional recommendations suggesting institutionalization of the child should be a practice of the past. Puescel and Murphy (1977) believe that the professional's thoughtful consideration and mature counsel will assist in shaping the child's future. Brazelton (1982) thought likewise, indicating that the professional needs to accept the negative forces of grieving but work to free up positive forces for interaction with the child as well. He indicated that the best behaviors of the child need to be emphasized to generate hope in the parent.

The problem is, of course, the quality of knowledge that the physician has regarding services and other resources available. The physician needs either to become knowledgeable in this area or know a knowledgeable resource to whom he/she can refer parents. Abramson, Bravink, Abramson and Sommers (1977) indicate the need for physicians to establish contact with mental retardation specialists so that they are available and know what services and resources are available in a community. Adams (1982) found that the effectiveness of the physician was due, in part, to the physician's years in practice and the participation in pre or inservice training in mental retardation.

Halpern and Parker-Crawford (1982) recount the experiences of nine young handicapped children and their families with a variety of human service institutions. These children were born in Michigan between the years of 1969 and 1974. Parents reported that physicians adequately described the cause and what was wrong with the child when a specific diagnosis was clearly possible. Parents reported being more dissatisfied with the physician's responses to questions about the implications of a particular problem for a child's future. Parents also indicated that physicians were usually not helpful in advising them as to what to do next or where to turn for services and support. More importantly, five of the nine parents reported that the confirming physician often seemed casual, extremely busy, or personally uncomfortable. It is clearly difficult and painful to have to communicate the news to parents that their child is handicapped. *But a number of parents reported that moment to be one when they most needed support and assurance that the future would be manageable. All the families reported that at the point of identification, however tentative, what they wanted most was honest, straight talk, a description of possible futures, and someone to give them a feeling of not being so alone.* Whether identification was sudden or gradual, these parental needs were consistent. From families' perspectives, many of the physicians with whom they were involved seemed reluctant to become personally involved. Whether or not this perception was accurate, its effect was to reinforce feelings of guilt, anger, isolation and fear brought on by facing the realities of having a handicapped child. Too frequently outcomes reported by physicians did not include adaptive functioning and a description of a child's strengths. These latter issues are important to the parent.

Halpern and Parker-Crawford (1982) concluded that a number of actions can be taken by the professional community to enhance the stability of families with handicapped children, and improve the quality of professional-parent interaction.

1. Professional training should include components that address the interpersonal as well as technical aspects of work with handicapped children and their families.
2. Each service system, especially the medical system, should have a clearly defined process that routinely comes into play when a handicapped child is identified.
3. All the service systems working with handicapped children should find means for more effectively utilizing parent support groups as a resource in improving parent/professional interaction, in assisting parents who are isolated or who have general support needs, in enhancing parent skills to meet their own needs, and in making services generally more responsive to families' needs.
4. Parent's knowledge of their child and experience in meeting their child's needs should be given greater weight as a source of assessment information. Assessment findings should report strengths as well as disabilities, and should include program recommendations.
5. Child advocates are an especially important resource in situations where there is a great deal of intra-family stress.

Parents are involved with professionals throughout the child's life and the parent-professional relationship is always one of reciprocity; sometimes the relationship creates profitable tension and other times critical stress. Both profitable tension and unproductive stress are often manifested in parent/professional relationships within the school environment. Vincent, et al. (1980) summarized factors which detract from a cooperative partnership and which are based upon assumptions by professionals and parents. The professionals may assume that the parents: (1) are not willing to use their home resources to work systematically with their handicapped child; (2) have unrealistic expectations for the handicapped child; (3) do not know how to teach their handicapped child effectively; and (4) need professionals to help them solve their problems because parents help to contribute to the child's problem. Parents on the other hand may assume that public schools: (1) do not have the resources to meet the needs of the severely handicapped student; (2) are not committed to meeting those needs; (3) do not recognize the family's commitment to and the skill with the student; and (4) do not want the parent involved in major decisions related to the severely handicapped student's educational program. All of these assumptions, if untrue, could create nonproductive stress and could unduly influence parents' relationships with professionals.

Although today most parent-professional interactions are occurring at the preschool and school levels, there is another group of parents for whom professionals need to exhibit a deep sensitivity. Many parents of adults who are severely retarded and who have never been institutionalized are tired, somewhat discouraged and disappointed. This discouragement and disappointment comes partially from the fact that they see an emphasis on preschool education which arose during the 1970s and an expanding array of services which have evolved as a result of P.L. 94-142. They realize that their son or daughter never had those benefits. Moreover, they see many children with handicaps similar to their own child's, functioning at a much higher level and therefore having greater potential because of the advantages which have occurred as a result of superior educational opportunities. These are the parents who spent years advocating through Associations for Retarded Citizens and other special interest groups for programs for their children; these are the parents who opened and conducted the preschool and school programs in the church basements or in private homes; these are the parents who had no professional help to assist them in how to teach their child and who developed their own techniques and methods to teach, some successful and some not successful. These parents are now older. Although they are discouraged, fortunately they see an array of community services—group homes, activity centers, and sheltered workshops that seem to have the potential of serving their handicapped son or daughter. They are now ready to turn over the care of their offspring to these organizations. Many of them have a difficult adjustment when they release their son or daughter who is now 25 to 40 years old to live in a group home. As professionals, we must be understanding of this reluctance to "let go."

From the above discussion it should be obvious that the parent-professional relationship is one of the most critical elements in the life of the severely retarded person and his/her family. The need for better communication and better understanding between professional and parent certainly can lessen the long range impact of having a handicapped child on parents and families. A supportive professional environment can lessen stresses and sadnesses which parents carry with them as they strive to help their severely retarded child function more normally in the environment.

Successful Parental Involvement

As late as 1965 most physicians in the United States were advising parents of severely retarded children to investigate the possibility of institutionalization as the best alternative for the care of the child. This was advice that probably seemed logical at the time because community services for this population of children were generally unavailable. Moreover, there was little knowledge about effective teaching of these children. Later in the 60's, research began to emerge that showed that these children could be taught and that parents as well as professionals could be teachers. The initial research focused primarily on the remediation of inappropriate behaviors. Hawkins, Peterson, Schweid and Bijou (1966), Wahler, Winkel, Peterson and Morrison (1965) and O'Leary, O'Leary and Becker (1967) conducted studies that eliminated disruptive behavior in children.

Risley and Wolf (1967) conducted one of the first studies which demonstrated that a mother could be used effectively to teach appropriate verbal behavior in a young child. However, at this time little of this information was being disseminated to parents. In fact, most parents who kept their children at home were providing tender care and a minimum of teaching. Since parents were not being informed about what their children could possibly learn, only the teaching of bare fundamentals was occurring. Schooling was the exception rather than the rule. Schools that did serve these children were seldom part of the public school system but instead were most often located in churches and private homes. Teachers were minimally trained. Despite the fact that most of these teachers were exceptionally devoted to their students, they did not assist parents in learning how to become effective teachers with their children.

In the 1970's, and especially towards the latter half of that decade, a proliferation of studies emerged demonstrating that parents could remediate inappropriate behaviors. Moore, and Bailey (1973) used a cuing procedure with a mother of a three-year-old girl who showed autistic-like behaviors and taught the mother to approve and disapprove of the child's behavior. As a result of this cuing process the child's responsiveness increased and maintained 7 months later. Merbaum (1973) taught a mother to use aversive stimulation in the treatment of her severely self-disruptive son. Whitman, Hurley, Johnson and Christian (1978) taught a mother to help remediate the inappropriate behavior for her institutionalized severely retarded son. Hanley, Perelman and Homan (1979) demonstrated that parents could successfully modify self-stimulatory behavior in the home. Thus, by 1980 it was well established that parents could be taught to remediate inappropriate behaviors of severely handicapped children. Since the manifestation of inappropriate behaviors that seemed unmanageable were frequently the cause of parents institutionalizing their child, by 1980 a technology had been demonstrated that would allow parents to remediate such behaviors in lieu of placing their child in an institution.

The 1970's also saw a major accomplishment in the demonstration that parents could be teachers of skills as well as remediators of inappropriate behaviors of their severely retarded children. Baldwin, Fredericks, and Brodsky (1973) published one of the first manuals for parents of the severely retarded and advocated that parents take an active role in the teaching of their exceptional child. They proposed the involvement of parents as teachers in self-help skills, personal hygiene, motor development, academic skills and language. This advocacy was a result of their experience in a classroom program for severely retarded children developed in the early 1970's in Oregon. This program involved parents in the teaching of their children through a process known as the lunch box data system. The lunch box data system taught parents to continue teaching the same program at home that was being taught in the school, teaching the next advanced step so that the child's teaching would continue from school to home to school and back again. It was found that children's rate of learning was significantly higher when parents and school cooperated in such a program as opposed to programs which were conducted solely in the school (Fredericks, Baldwin & Grove, 1973, 1976).

Concurrently throughout the country others were demonstrating that parents could teach their handicapped children. Seitz and Hoekenga (1974) demonstrated that parents could teach children language. Hanson (1977) focused on Down syndrome infants, with parents teaching a variety of skills to their children over a three year period. Arnold, Sturgis and Forehand (1977) demonstrated that a mother could teach communication skills to a retarded adolescent child. Angney and Hanley (1979) showed how parents of a child with Down syndrome taught the child to walk unsupported. In 1981 Filler and Kasari demonstrated that parents could be taught to teach their 4- and 14-month-old infants major motor tasks such as rolling from prone to supine, tracking visually, auditorially localizing a sound, and reaching for an object. They argued that parent training of severely retarded infants was absolutely essential.

During this same period, two other movements were significantly impacting on the involvement of parents in programs for children with severe retardation. One was the Handicapped Children's Early Education Program (HCEEP) sponsored by the Bureau for the Education of the Handicapped. This program, established in 1969, had as a requirement for all early childhood model demonstration projects, the inclusion of a parent component. Parents were involved in multitudinous ways—as teachers both at home and in centers, visitor guides, volunteers, advocates, public relations personnel, and members of advisory boards. Above all they were considered an essential element of every early childhood program (see Gentry and Olson, this volume for more information).

Some notable early childhood education programs which incorporated parents as an essential element were developed as a result of HCEEP. Perhaps the most publicized was the PORTAGE Project which used paraprofessional workers to train parents who in turn taught their severely handicapped preschool children (Shearer, 1976). The RIP Project in Tennessee used parents as teachers in the classroom and demonstrated that they could be effective teachers of their severely handicapped children (Wiegerink & Parrish, 1976). Finally, the Teaching Research Data Based Classroom preschool model used parents as volunteers in the classroom and as home teachers using the Lunch Box Data System (Staff of the Teaching Research Infant and Child Center, 1982). These three programs, developed under the auspices of HCEEP have maintained over time not only in their own environments in which they were developed—Wisconsin, Tennessee and Oregon—but have proliferated throughout the world, reflecting their universality and effectiveness.

The other event in the 70's that impacted on parent involvement was the passage of Public Law 94-142. Parents had been actively involved in lobbying for this legislation. The National Association for Retarded Citizens, whose parent membership consists primarily of those with children with severe retardation, was a prime advocate together with the Council for Exceptional Children. Once this law was passed, the role of parents was well recognized, and they were at least, in legal terms, equal partners with schools in educating their children. The testimony before Congress which resulted in the strong parental participation clauses in P.L. 94-142 identified three major roles to be played by the parent. The first role was the decision maker about the education of their handicapped child. The second role assigned parents more active participation to assure the child's rights, to increase school accountability and to represent their child's best interests. The third role was that of teacher of their handicapped child (Turnbull, Turnbull & Wheat, 1982).

Yet, there are those who maintain that this progress was only the beginning of parental involvement; parents needed to have a much more active role in the teaching of and decision making for their child. Hawkins and Hawkins (1981) argued that the primary goals of education of severely retarded persons should be oriented toward their functioning within the family and home environment and that parents therefore need to be more heavily involved in the education of their severely handicapped children. Fredericks, Toews, Petersen, Templeman, Bunse, Trecker, Egan, Hendrickson and Muthersbaugh (1984) advocate the use of parents at the secondary level more extensively than has been previously advocated in the literature. These investigators envision the parent of the adolescent becoming more involved in the education of their son or daughter because of the type of argument voiced by Hawkins and Hawkins (1981). More of the skills of the adolescent student need to be taught in the community and many of those skills need to be taught in the home. Consequently the parents need to assume the role either as the primary teacher of many of these skills or in some cases as the person who teaches the student to generalize skills which have been taught in the classroom environment.

Fredericks (1983) also advocated that parents be actively involved at the secondary level in the assessment process to determine curricular priorities for the adolescent. By the time a severely retarded youth reaches high school, only a few years of education remain. Yet, if one examines the plethora of skills that need to be taught, one can be overwhelmed by the scope. Therefore, to provide focus to the curriculum Fredericks (1983) advocated a community assessment process that examined the requirements of various residential and vocational placements in the community, assessed the student as to his/her most probable placement, and considered the immediate requirements of his/her school and home environment. It was very useful that the parent be part of this assessment process. In addition to being a prime participant in the assessment process of the student and performing the dual roles of teacher (both primary teacher and generalizer), Fredericks, et al. (1983) advocated that the parent spend more time in the secondary classroom of the student in order to become familiar with the best methods to teach an adolescent with severe retardation and also to be more conversant with the vast curriculum that must be taught.

Thus, parental involvement seems to be increasing. The literature contains many examples of such involvement. A few citations will illustrate the scope of parental involvement at all age levels. Piper and Ramsay (1980) showed the changes in mental development for 37 Down syndrome infants over a six-month period as a result of daily stimulation and maternal involvement. Harris, Wolchik and Weitz (1981) reported on the acquisition of language by 11 preschool autistic children. The children all showed significant gains in pre-speech and speech skills which were related to degree of parental teaching.

Parents have also been found to be effective teachers of school-age children and adults. The Staff of the Teaching Research Infant and Child Center (1982) through the Lunch Box Data System demonstrated that it works effectively in school-age as well as preschool programs. Stromer and Miller (1982) describe a program for deaf multiply handicapped children in which data were collected demonstrating the effectiveness of parent involvement. At the adult level, Fowler, Johnson, Whitman and Zukotynski (1978) found that a parent of a 24-year-old noninstitutionalized profoundly retarded woman could teach hair brushing, tooth brushing, face washing, and learned to increase her daughter's compliance and to decrease noncompliance and aggressive responses during the self-help training.

At least one state has committed resources to a statewide network of parent trainers to help parents teach their retarded child. The Oregon Parent Training Network consists of parent training sites located in 21 of Oregon's 36 counties. The network was established in 1974 and, although initially it was designed to serve retarded children of all ages, its current priority is the birth to three-years population. Either in a clinic setting or the child's home, the parents learn to teach their child self-help, language, motor, pre-academic, academic and social skills. Parent trainers also teach parents to remediate inappropriate behaviors that parents identify as disruptive. Parents are usually seen by parent trainers every week. During this time, based on data gathered by parents, the parent trainer adds new programs or modifies existing programs, teaching the parent new intervention skills as necessary.

Data for a nine-month period (Oct. 1980–June 1981) are presented from the parent training network in Table 8.1 (Moore, Fredericks, Rogers & Fink, 1982). Table 8.1 indicates that 309 families received services in the 21 sites during this nine-month period because they needed assistance in teaching their severely handicapped child. (Almost all of these children were severely retarded.) With these 309 families, 1,797 individual programs were implemented with their children. Seventy-one percent of these programs were in the curricular areas of motor, language and self-help, indicating the focus on the young severely handicapped child. By the end of the reporting period 1,007 of these programs had achieved their objective and 547 were still ongoing. Two hundred and forty-three programs were not completed, primarily because of families moving, children's health problems or children placed in school programs which assumed the responsibility for the conduct of the programs. Only 17 of these programs were not completed because of parental dissatisfaction. Certainly the response by this number of parents in a state with a population of two million, if representative, would indicate a widespread need throughout the United States for this type of service.

Table 8.1 Oregon Parent Training Network Program Data With Developmentally Disabled Population from October 1, 1980 to June 30, 1981

	Developmentally Disabled	
Categories	**Number**	**%**
I. Number of Families Served	309	100
A. Terminated	131	42
B. Families Active	178	58
II. Children Served by Age	309	100
A. 0–3	135	44
B. 4–6	87	28
C. 7–12	45	15
D. 13–16	31	10
E. Adult (16+)	11	3
III. Number of Programs by Areas	1,797	100
A. Self help	202	10
B. Language	360	20
C. Behavior	270	15
D. Motor	734	41
E. Academic	231	13
IV. Status of All Programs	1,797	100
A. Successfully Terminated	1,007	56
B. Unsuccessfully Terminated	243	14
C. Ongoing as of June 30, 1981	547	30
V. Status of All Terminated Programs	1,250	100
A. Successfully Terminated	1,007	81
B. Unsuccessfully Terminated	243	19
VI. Average Number of Programs by Child	5.8/child	

Issues and Concerns

Much progress has been made over the years and, especially during the last 15 years, in the successful involvement of parents in programs with severely retarded children. Yet parents of severely retarded children are not a homogenous group. Consequently, a variety of concerns and issues are present and emerging with which professionals and parents together must cope during the forthcoming years in order to arrive at solutions that might best benefit children. Frequently these issues reflect the heterogeneous nature of parents, and professionals should be aware of those differences.

One issue that demonstrates the differences in parents' points of view is deinstitutionalization. Parents of younger children and parents who have never institutionalized their children generally stand firmly in the camp which favors deinstitutionalization and the enhancement of community services. But what about parents who have institutionalized their child? How do they view deinstitutionalization, especially when it involves their own son/daughter who is now an adult? Willer, Intagliata and Atkinson (1981) conducted structured interviews to determine the extent to which families of the mentally retarded experience a crisis upon deinstitutionalization of a family member. These interviews indicated that approximately 50 percent of the families experienced a crisis, even if the family member was not returned to the parents' home. Meyer (1980) mailed questionnaires to parents of institutionalized mentally retarded persons to determine the placement that they preferred for their retarded offspring. An overwhelming majority chose the institution over the group home and supervised apartments.

Thus we have a large segment of parents of severely retarded people who view the general trend towards deinstitutionalization as not acceptable for their child and who frequently actively oppose deinstitutionalization. The tendency of many professionals is to ignore this population of parents or to look upon them with disdain because of their attitudes. One must remember the circumstances under which they institutionalized their offspring. In many cases they were advised and counseled by professionals to institutionalize their son or daughter because there were no other services. These parents have adjusted to that institutionalization; their offspring have adjusted to that institutionalization; and now, suddenly in their advancing years, they are being asked to accept another alternative for which they have not been adequately prepared. Professionals must be concerned about this situation and must make efforts to familiarize these parents with group homes and the advantages of deinstitutionalization. Above all professionals must understand the reluctance with which these parents approach this new "movement."

The deinstitutionalization movement epitomizes the polarization which can occur among parents on a specific issue regarding their retarded offspring. It occurs because of changing times which bring new programs and opportunities for severely retarded people, and so, depending on the parent's age and experience, different perspectives are formulated. We see another example of these changing times in the attitudes of professionals towards parents.

Many professionals and primarily physicians look upon parents of handicapped children as going through various stages of adjustment and believing that the parents of handicapped children feel that a tremendous negative influence has come into their lives (Love, 1970; Menolascino, 1974). Dunlap (1979) indicated that the majority of the families that he interviewed did not perceive the disabled members having a substantial negative influence on the families. Respondents of this study seem to have handled the problem created by a disabled person with no serious consequence to the family. Dunlap's (1979) study however, was predominantly conducted with a rural and poor black population in the state of Alabama. A similar informal survey conducted among parents in Oregon comprising a wide spectrum of socio-economic situations indicated that the parents are more actively pursuing assistance at an early age. It is not uncommon, for instance, for the parent of a newborn Down syndrome infant to be seeking assistance from a parent training clinic within six weeks after the infant's birth. This phenomenon may be a function of the wide array of services available in Oregon and the publicity given to the Parent Training Network within Oregon. Data from these small samples suggest parents do not have to have negative feelings about their child or their situation or to have progressed through the stages of adjustment proposed by Menolascino (1974). This is not to say that parents do not experience grief when their child is identified as severely retarded. However, professionals need to be careful about generalizing the stages of emotional reaction which parents go through. Professionals must bring to their interactions with parents a greater sensitivity based on the knowledge that parents also have individual differences.

Occasionally parents do experience the need to have some relief from the handicapped member. The difficulty in finding relief is almost in direct proportion to the severity of the handicapping condition. The more severe the handicap, the more severe the daily stress may be, the more the parent may need respite services, and the less available respite services may be. Respite services seem to be one of the more ephemeral parental services. A respite service may be established in a community, function for awhile, and then disappear. In its place may emerge another alternative which may offer a totally different service. In many communities, respite services seldom or never exist. Such services, even when they do exist, are so poorly publicized that many parents are unaware of their availability. Thus, the provision of respite services emerges as a critical service need for many parents in many communities. Further, such services need to be varied to meet the individual needs of families.

Currently, there seems to be a major groundswell of concern for the adequacy of programs at the secondary level. It is as though professionals have suddenly realized that there is a high school population of severely retarded adolescents who must receive appropriate services. Associated with this concern are two issues: 1) the need to involve parents more actively at the secondary level; and 2) the need to assist parents and professionals to agree on realistic expectations for the handicapped secondary student.

Public Law 94-142 has increased the involvement of parents in school-age programs, at least in the development of an individual education plan (IEP) for the severely handicapped child. Many have considered this the ultimate victory for parents. Our view, however, is that this is only the beginning of parental involvement. We have seen an increase in the awareness on the part of teachers at all levels for the need for parental involvement in the education of severely handicapped students. This has long been recognized in preschool programs where parents need to be involved in language and communication acquisition of the child and the generalization of those behaviors to insure that they become an integral part of the child's repertoire of skills. One cannot toilet train a child solely in a classroom; the parents must be involved. Children will acquire new skills faster if both parents and school are involved and thus schools should be actively seeking cooperative arrangement with parents (Fredericks et al., 1983). Likewise, parents need to become more involved at the secondary level because of the need for community and home training of the secondary handicapped student. Frequently this training can only be accomplished with parental help.

However, despite the movement toward more parental involvement, the data on the degree of parental involvement are not encouraging. For instance, Stile, Cole and Garner (1979) indicate that there is evidence that attrition is often high in parental involvement programs. Certainly the data suggest a higher percentage of preschool parents are involved in programs for their handicapped children than are parents of elementary-aged children and the least parental involvement is at the secondary level (Fredericks, 1983). So not only is there attrition occurring at each level, but that attrition becomes more pronounced as the youngster gets older. This trend needs to be eliminated in order to elicit the needed parental involvement at the secondary level.

Associated with parental involvement at the secondary level is the need to develop among parents and professionals realistic expectations for adolescent handicapped students when they reach adulthood. A survey by Venn, DuBose and Mertler (1977) indicated that there were significant differences in expectations for the achievements of children between parents and teachers. Discussions with teachers by the present writer frequently indicate that this is a considerable problem. Parents either expect greater achievement from their child than teachers do or frequently parents are not willing to have their youngsters take risks which will allow them to be exposed to community learning situations. Thus, it seems that parents err in both directions, holding back the youngster or expecting too much. Fredericks, et al. (1983) have postulated that involving the parent more actively in the secondary program will create more realistic expectations by the parent and may also make the parent a more successful advocate for adult programs for their severely handicapped adolescent.

Associated with the difficulty of being able to arrive at realistic expectations is the deep parental concerns about the availability of services for their offspring after they leave school. In many communities adequate space in the sheltered workshop or the activity center is not available for individuals requiring such services. There are frequently long waiting lists for group home placement. These situations create anxieties among parents that confuse their post-school expectations. In only a few notable communities are found satisfactory alternative programs of community placement for vocational training (Beebe, 1982).

Another concern of parents is the placement of their son or daughter and his/her financial support after they are deceased. Concerns are twofold. One concern focuses on the long-term quality of post-school programs both residential and vocational. Parents need a guarantee that quality will be maintained in community programs. Unfortunately there is little evidence to indicate that mechanisms to maintain quality are built into these programs. Systematic plans seldom exist for periodic upgrading of staff through inservice training or the training of new staff. Evaluation of program quality other than paperwork reports seldom exists. Consequently, parents of older severely retarded persons are anxious about whether the quality of a program will be maintained after they are no longer available as advocates for their son or daughter.

Anxiety is also manifested by some parents as they consider providing financial security for their retarded offspring. Many severely retarded persons are dependent solely upon public assistance, which may also cause parents anxiety because of the tenuous nature of federal or state social assistance programs. The more fortunate parents who can provide support for their youngsters must cope with a maze of federal and state laws regarding inheritance, trusts, and guardianship for the provision of financial support for the handicapped person. Only recently have lawyers and accountants attended to the complexities of this problem. Parental need is great; professional assistance is minimal. Beidel and Marshak (1983) have summarized the difficult decisions which parents of severely handicapped individuals face in this area.

Parent advocacy must continue to grow. Parent advocacy was largely responsible for Public Law 94-142. Certainly parent advocacy is going to be necessary to obtain improved post-secondary programs that will maximize normalization for students with severe handicaps. Brown (1982) has proposed that parents advocate for better employment in the community rather than for better sheltered employment. An employment program located in Madison, Wisconsin has demonstrated that community employment is possible (Beebe, 1982). Future changes will come about through parental support. As noted above deinstitutionalization of people with severe handicaps was the beginning, with movements to sheltered employment and group home living a second stage. Hopefully, movement to employment in the community will be the third stage, perhaps concurrently with greater use of shared apartment living. Parent advocacy will make this third stage a reality.

SUMMARY

This chapter has focused on the impact of a severely retarded child on the family and has traced parental involvement in programs from early childhood to adulthood. Parent involvement has grown in terms of both advocacy and program participation. Yet there are still many needs. Parents need to be more actively involved in the education of their child at the secondary level and need help in expanding services at this level. More respite care is needed; better legal assistance is required and more assurance regarding the availability and quality of post-secondary residential and vocational programs is required. Although in need of assistance from the professional community, this chapter has argued that parents are a key element in the education, training and advocacy for their severely retarded son or daughter.

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CHAPTER 9/
THE EVALUATION OF SEVERELY MENTALLY RETARDED POPULATIONS

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References

INTRODUCTION

"Evaluation" is a process of gathering, organizing and/or analyzing information in a manner which results in some action-oriented decision (cf., Stufflebeam, Foley, Gephart, Guba, Hammond, Merriman, & Provus, 1971; Sax, 1974; White, 1980a). The teacher conducts evaluations to decide where a child's instruction should begin; the physician to decide upon a course of chemical treatment for a seizure prone child; and the administrator to select a "model program" for adoption within the district. The potential uses for evaluation are limitless; and each new purpose may require a different evaluation strategy. This chapter will review historical and current decision making needs concerning the severely mentally retarded and examine the usefulness of prevalent evaluation strategies to meet those needs. Through that review it is hoped that the reader will develop an appreciation for the changing nature of special education and the need to be continually reexamining one's evaluative tools.

The evolution and development of evaluative strategies in special education has generally reflected changes in societal expectations for handicapped individuals. Prior to 1600, society held virtually no expectations for the eventual habilitation of handicapped persons. Humanitarian interests dictated "treatment" in the form of food, shelter and clothing, but education or training in the modern sense were generally not considered (MacMillan, 1977). It is not surprising, therefore, that persons were simply categorized as "weak, odd or poor" (Hewett & Forness, 1977; Farber, 1974) and that evaluative strategies amounted to little more than a casual observation of a person's ability to survive without special support.

During the 1700's there was a general awakening of humanitarian and scientific interest in various disabilities (Bruininks & Warfield, 1978) with a concomitant awareness that some handicapped persons could be successfully habilitated. "Success" in the treatment of handicapped persons was not universal, and the need to discriminate among various types of handicaps increased. It was no longer sufficient to group the mentally retarded, mentally ill, blind, lame and deaf under the category of "misfit" (Farber, 1974). Specialized schools began to emerge (primarily for the sensory impaired) and even most institutions began to adopt the posture of "schools" making sincere efforts to habilitate their residents (Kanner, 1964). Specialization required methods for reliably matching pupil characteristics with treatment alternatives. Although the evolution of those evaluative strategies was slow and concentrated on the sensory or physical abilities of handicapped persons, the development of treatment-oriented diagnosis was established by the end of the eighteenth century.

While attempts to habilitate children with sensory and/or physical deficits met with some success and encouraged the development of more refined procedures for diagnosis and treatment, early work with the severely mentally retarded and mentally ill was generally ineffective. Interest in distinguishing among such persons with respect to specific educational need decreased and by the mid-1800's most institutions began to replace the "education model" with the "pity model," returning to simple custodial care (Baumeister, 1970; Lazerson, 1975). Interest in diagnosis did not diminish, however. There was still a need to distinguish which children were "idiots or imbeciles" and could not be successfully treated (under existing practices), from those who were simply sensory/motor impaired and might be successfully treated. Since the fundamental distinction to be made was physiological, diagnoses were primarily medical in nature. Indeed, the failure to successfully habilitate the mentally retarded through instruction eventually resulted in the proposal of a "medical solution" to the problem—total segregation and eugenic sterilization (Dugale, 1877; Goddard, 1912; Pitkin, 1928).

It was eventually conceded that sterilization was an inappropriate and ineffective means of "protecting society," but the possibility of such an approach fanned interest in the identification of differing symptom patterns and their etiology, especially from the medical/genetic standpoint (MacMillan, 1977). While that interest eventually led to the discovery of methods for the prevention and alleviation of certain handicapping conditions, early successes also led to an over reliance on medical diagnoses and treatment. Society placed a premium on the control of physical symptoms and the removal of "deviants" from the community through institutionalization. Medical diagnoses often proved satisfactory for those purposes, and by 1910 most states required a physician's certification before a pupil could be excluded from school.

Educators then began to realize that medical diagnoses alone could not account for a sizable proportion of the children who had difficulty in learning. More refined diagnostic tools were required, a need which was met through the introduction of the concept of "mental age" by Binet and Simon in 1905 (MacMillan & Meyers, 1977). By 1947 the role of IQ tests in education was sufficiently established to be recognized by the California legislature and a child could now only be classified as mentally retarded on the basis of an IQ score determined by a qualified psychologist. However, IQ tests alone were proving unsatisfactory for anything but preliminary identification, and society was moving into a new period of concern for the "education and welfare" of the handicapped (Mercer & Richardson, 1975). Tests began to emerge which identified specific areas of developmental concern, rather than simple statements of "overall level of functioning" (e.g., the *Vineland Social Maturity Scale*; Doll, 1947).

During the 1950's concern for the education of the entire spectrum of handicapped individuals was beginning to take root. Various categories of mildly handicapped children were becoming formalized (Hallahan & Cruickshank, 1973) and by 1960 most currently used diagnostic categories for handicapped persons were used with at least a modicum of uniformity throughout the United States. Then educators began to question once again the validity of the diagnostic process.

For centuries the educational community had been interested in the classification of children. At first, concern was only for the exclusion of children who would not benefit from existing educational practices. Later, attention turned toward the "medical" remediation and prevention of handicapping conditions, and finally for the "fine-grained" discrimination among children with subtle differences in the etiology or manifestation of handicapping conditions. The educational community was lulled into the belief that by determining exactly how and why an individual was handicapped, appropriate grouping of those children would "solve the problem." As long as the treatment options remained medical or a matter of segregation, perhaps that was true, but when concern began to shift from the protection of society to a sincere interest in the development of the handicapped individual, existing classification systems proved unsatisfactory.

Specific diagnostic approaches were often too simplistic and could result in the inappropriate classification of a child. For example, the recognition that a disproportionate number of minority children were diagnosed as "educably mentally retarded" eventually led to the realization that available intelligence tests had severe cultural and racial biases (Dunn, 1968). In other cases the generic label resulting from a diagnosis might be essentially accurate, but simply did not provide enough information for selecting appropriate treatment alternatives. Two severely mentally retarded children may indeed share something in common which could be called an "intellectual deficit," but require vastly different instructional approaches in order to learn. In still other cases effective educational practices did not exist to meet the needs of handicapped individuals, and the process of searching for ever more refined labels did not solve the problem. As state and federal legislatures were finalizing the codification of diagnostic categories for handicapped individuals, society began to move into a new phase of concern for handicapped persons as individuals and for the development of more effective service alternatives (Mercer & Richardson, 1975; Bruininks & Warfield, 1978).

CURRENT PRACTICES: OUR CUMULATIVE INHERITANCE

As the inheritors of the "civil rights movement" in special education, educators today are presented with an obligation to make decisions which never before had to be made. The question is no longer simply "to exclude or not to exclude" (see Noel, Burke & Valdivieso, this volume). The decisions at issue now presumably concern a much broader range of specific "who, what, where and how's" of service delivery, and focus has shifted from the generic "category" to the specific "individual." Current evaluative practices designed to facilitate the realization of that commitment are many and varied.

Screening and Diagnosis

Screening is the process of identifying children who may be in need of special assistance; diagnosis is the process of confirming the suspicion of need and pinpointing the specific nature of the handicap. At times screening will lead directly to or incorporate a specific diagnosis, but more commonly screening and diagnosis are two distinct operations.

Medical Approaches Medical approaches for the identification and classification of handicapping conditions were among the first to be formalized and remain (in refined form) the mainstay of early identification efforts today. Screening routinely begins a few moments after birth with a check for major clinical manifestations of handicapping conditions or known genetic anomolies (e.g., Down syndrome), blood and urine samples to test for metabolic disorders (e.g., PKU), and the use of the APGAR rating scale to identify children who might be "at risk" for developing abnormally because of difficulties with heart rate, breathing, muscle tone, reflexes or circulation (Apgar & James, 1962). Less routinely, at the request of the parents, assessments can even be conducted prior to birth through a process called amniocentesis which permits the identification of certain genetic disorders in utero.

In some cases the results of a medical test will indicate the need for specific medical intervention. If a phenylketonuric child is placed on a special diet, most of the toxic build-up of phenylalinine in the system can be avoided and the resultant intellectual impairment obviated or minimized. In other cases a classification will prompt nonmedical action, as in the case of a Down syndrome child. Down syndrome children run a high risk of being mentally retarded and for developing a wide range of health problems. While no immediate medical treatment might be indicated, careful monitoring of the child's health should be continued to diagnose any treatable physical problems as soon as they occur and enrollment in a special infant education program is generally advised to minimize possible developmental delays. Finally, some medical screening procedures will not lead to a specific diagnosis, but will identify children whose health is such that they are "at risk" for developing abnormally. To confirm the presence of a handicapping condition in such cases, additional medical or nonmedical tests must be conducted.

Developmental Screening Although a large proportion of severely mentally retarded children are identifiable at birth or shortly thereafter, some may not be identified until several months or possibly years later. Initial identification of such children may follow from general parental concern or as a result of routine examinations by a physician. Once suspected of a developmental delay, several formal assessment instruments might be employed to clarify the potential problem. Until recently, early developmental screening instruments were almost all norm-referenced on a sample of nonhandicapped children. That is, they described the sequence in which nonhandicapped children "usually" learn and develop new skills (e.g., the *Denver Developmental Screening Test*; Frankenburg & Dodds, 1970). Several screening instruments have now been developed specifically for use with children suspected or known to have severe developmental delays (e.g., the *TARC*, Sailor & Mix, 1975; The *Portage Project Checklist*, Bluma, Shearer, Frohman & Hilliard, 1976). Instruments developed with the handicapped in mind may concentrate on specific developmental concerns which will be of interest during later program development, but for the initial identification of a handicapping condition per se, they are not likely to prove any more effective than instruments normed with nonhandicapped children.

Identifying Primary and Secondary Handicapping Conditions Many diagnostic classifications only indicate the probability of certain functional handicaps. A Down syndrome child may be identified with some precision, but the eventual development of the child cannot be predicted with certainty. While Down syndrome does account for roughly one-sixth to one-third of the severely handicapped population, some of the children affected are only mildly retarded (Snell & Renzaglia, 1982). Many Down syndrome children may also demonstrate a number of physical problems like chronically poor health or sensory deficits, which can contribute to developmental delays that can be misinterpreted as the result of general intellectual deficits (Hayden, & Haring, 1976; Patrusky, 1980). The problem in separating the effects of sensory/physical problems from general intellectual deficits is especially acute with young noncommunicative individuals. Such individuals do not generally respond to traditional methods for vision and hearing assessments, but it is not clear whether their failure to respond is a function of sensory deficit or difficulty in understanding the evaluator's directions.

Attempts have been made to develop ability tests which can be used with children demonstrating severe vision and hearing deficits (e.g., the *Callier-Azusa Scale*; Stillman, 1977), but such tests do not help in the early identification of vision and hearing impairment per se. In the assessment of vision and hearing, the general movement has been toward the use of basic operant training procedures. The child is trained to respond to two very different stimuli (e.g., a bright light vs. no light) and reinforced for responding in some age-appropriate manner (e.g., an infant might be reinforced with the activation of a musical toy for kicking a board when the bright light is displayed). When reliable responding to the training stimuli has been achieved, stimulus dimensions are systematically altered to test the limits of vision or hearing. In some cases the training procedures have actually resulted in the improvement of demonstrated visual or auditory discrimination skills in children previously believed to be functionally blind or deaf (cf., Stolz, & Wolf, 1969; Fulton, & Spradlin, 1971; Decker, & Wilson, 1977).

The Impact of Screening and Diagnosis Most educators value early identification and diagnosis of handicapping conditions because it allows the earliest possible intervention. However, great care must be exercised while interpreting the results of early screening or diagnostic information. Children who appear to be severely intellectually impaired may only have a moderate intellectual deficit confounded by the presence of sensory impairments; children precisely classified in a diagnostic category associated with a high incidence of severe mental retardation may be only mildly retarded; and children demonstrating serious developmental delays may respond well to early infant training and education programs (Fewell, 1982; Allen, 1978; Bricker, & Dow, 1980).

The selection of specific intervention strategies on the basis of preliminary diagnostic results should also be guarded. Even in cases where there is a clear need for medical intervention, it is important to maintain a broad perspective of the child's overall developmental needs. Attempts to control a child's seizures or "hyperactivity," for example, should not result in the use of a drug dosage which obviates the child's ability to effectively interact with the environment. Some balance must be sought—reasonable control of the physical problem, without severe impairment of the ability to learn.

Finally, despite the fact that most parents and professionals will use early screening and diagnostic information as the first step in determining how best to meet the needs of the child, the same information may also be used as the justification for much different courses of action. Institutionalization is still considered a legally viable alternative. As recently as 1979 the U.S. Supreme Court ruled that a child is not entitled to counsel or an advocate if the parents wish the child placed in an institution. As noted by Biklen (1981), it was the court's opinion that, "parents generally act in the child's best interests," and in grim recollection of the days when the physician was the sole source of guidance regarding a child's needs, the court went on to say that, "What is best for a child is an individual medical decision that must be left to the judgement of physicians in each case." The courts have also upheld the right of parents to forbid treatment or operations to be performed on their handicapped children, even when that refusal will result in the premature death of the child (cf., Bothman v. Warren B., California Court of Appeal, 1979). Those opinions may now be tempered by an increasing concern for "Baby Doe," but it is important to realize that the historical "segregationist" purposes for screening and diagnosis have not been left behind. At best, they are being joined by other decision alternatives.

Individualized Education Program (IEP) Planning and Evaluation

After the initial identification and confirmation of a handicap, Federal Law P.L. 94-142 requires that an Individualized Education Program (IEP) be developed for each handicapped child which specifies (among other things) the services which a child will receive, annual goals, intermediate objectives, and the plan for monitoring progress toward those objectives and goals. The importance of the IEP in providing overall focus and direction for a program cannot be overstated. If that focus turns out to be inappropriate, then valuable time will be lost and the child may actually worsen for lack of effective services. Unfortunately, IEP development is a complex process, and most current evaluation strategies for assisting in that process are not as helpful as one might hope.

The Range of Concerns A severely handicapped child may require intensive assistance in the development of skills normally acquired by a nonhandicapped preschool child, and those basic needs can easily extend into adulthood. An older severely mentally retarded individual will need to develop viable independent living skills, vocational skills and community integration skills. Given the high incidence of health, physical and sensory handicaps found in the severely mentally retarded population, one must also consider the possible need for medical intervention, physical or occupational therapy, speech therapy and/or special prosthetic aids for hearing, vision, posture, eating, object manipulation, communication or locomotion. Severely mentally retarded individuals also often display one or more "maladaptive" behaviors which should be reduced or eliminated; and since severely mentally retarded individuals will invariably progress more slowly than their normal counterparts, assessment instruments need to measure fine gradations of development. In short, assessments must cover a broad range of possible concerns in great detail.

For the most part, the need for breadth and detail has been adequately met. Instruments are available that range from less than ten items in length (e.g., the *Early Identification Screening Instrument*, Baltimore City Public Schools, 1980) to more than 2,400 items (e.g., the *Behavioral Characteristics Progression*, Santa Cruz County, Office of Education, 1973). Some instruments are quite focused in terms of the skill areas addressed and/or the type of individual for whom the scale was developed (e.g., the *Assessment of Auditory Functioning of Deaf-Blind Multihandicapped Children*; Kukla & Connolly, 1979), while others are broad in scope (e.g., the *AAMD Adaptive Behavior Scales* assess a total of 24 "domains" and were developed with mentally retarded people ranging in age from three to sixty-nine years; Nihira, Foster, Shellhaas & Leland, 1974). Actually, there may be a danger of selecting an instrument with too much detail, thereby reducing the efficiency of the decision-making process, and leading to a sort of "information overload" (White, 1980a). To avoid that problem, Sailor and Haring (1978) suggested a multilevel assessment approach, starting with basic screening instruments to identify major needs, and then progressing through successively more detailed assessments in each area of concern to determine precise educational needs.

Adaptive Skill Assessments Although many instruments provide sufficient breadth and detail for initial assessments, various handicapping conditions may require considerable adaptation in assessment procedures. The need for some adaptations may be obvious and straightforward, like allowing a nonvocal child to use manual English or a picture board when answering assessment questions which normally require an oral response. The need for other adaptations may be more subtle. What, for example, is an item like, "imitates 3-block bridge" supposed to assess? If it is to assess fine motor control, then a child without arms or legs and no skill with prosthetic devices will probably fail the item. If the real purpose of the item is to assess whether the child has the cognitive skills necessary to imitate complex actions (and the issue of "fine motor" is not important), then some method should be found which allows the child to demonstrate that cognitive ability within the range of his or her physical capabilities.

A few instruments provide guidance in the selection of possible adaptations. The *Uniform Performance Assessment System* (Haring, White, Edgar, Affleck & Hayden, 1981) indicates that it is indeed the cognitive ability to "imitate" that is important in the "3-block bridge" item, and that the use of blocks is simply a convenient method of assessing that ability with most young children. One might debate whether that is what the item *should* be designed to measure, however. A similar item, "imitating an adult, child will build a pyramid of 6 blocks," is listed on the motor scale of the *Pennsylvania Training Model Individual Assessment Guide* (Somerton-Fair & Turner, 1979), so one might reasonably assume that the function of the item on that test is to assess a physical/motor skill. Attempts have been made to develop assessment scales which fully define the "critical function" being assessed by each item and to provide specific suggestions for various adaptations which might be used with different types of handicapped children (e.g., the *Adaptive Performance Inventory,* Consortium on Adaptive Performance Evaluation, note 1). Such instruments are still generally in the experimental stage of development and not widely available.

Adaptive/Alternative Skill Development Sequences While normal children follow a fairly well defined sequence of skill development, that may not be the case with the severely handicapped. Most children will develop a wide range of fine and gross motor skills long before they begin to speak in complex sentences, but the orthopedically handicapped child might learn to speak without ever having limb control. Each aspect of the handicapped person's development must be treated as potentially separate from other aspects. Specific adaptations at one point in a continuum of development may even obviate expected developmental sequences in the same general area of concern. For example, adequate head control is a prerequisite for normal walking, but not for the use of a motorized wheelchair. If an individual fails to pass the basic motor item concerning head control, the tester cannot simply stop assessing "higher level" gross motor development. The assessment must continue up the scale to identify items where possible alternative skills might be developed which would allow partial accomplishment of desired ends. Many available instruments provide special item sequences to assess common adaptive skills (e.g., wheelchair use, nonoral communication). Aside from standard adaptive sequences, however, none of the widely available instruments provide much guidance concerning the way in which individualized adaptations might alter established developmental sequences, or how such changes can be taken into account when deciding which skills to assess or teach and in what order.

Placing the Results in a Meaningful Perspective Once an accurate and comprehensive assessment of an individual's specific abilities and deficits has been completed, there remains the task of establishing instructional or therapeutic goals and objectives for the coming year. With the nonhandicapped individual one would usually begin instruction in each major skill development sequence at the point the individual began to fail items, and continue up the established sequence of items as each new skill is mastered. Given the breadth of concerns and the possibility of significant departure from normal or typical developmental sequences, that is not usually a recommended option with the severely handicapped. Normal developmental sequences (or, alternatively, special sequences developed for certain types of handicapped individuals) may provide guidance in some areas with some individuals, but they cannot be relied upon for guidance in most cases (White, 1980c).

Unfortunately, most available instruments do arrange item sequences to reflect "typical" skill development. For example, the *Uniform Performance Assessment System* (Haring, et al., 1981) and the *Portage Project Checklist* (Bluma, et al., 1976) were both developed specifically for use with the handicapped, but the underlying item sequences follow a "normal development" model. Other scales avoid reference to normal developmental models by ordering items in terms of the frequency with which a group of severely handicapped individuals failed each item. That is, the greater the percentage of individuals failing an item, the higher its presumed level of difficulty and the further along the sequence of items it was placed. Pass/fail ratios at any given point in time do not necessarily reflect relative difficulty or the order in which skills *should* be taught. Such ratios may simply reflect what *has* been learned, and that could just as well be a function of opportunity rather than difficulty. That is a particular concern with instruments like the *AAMD Adaptive Behavior Scale* (Nihira, et al., 1974) and the *Balthazar Scales of Adaptive Behavior* (Balthazar, 1971) since those scales were developed in residential institutions—environments which may provide substantially different opportunities for learning and development than alternative placements. In recognition of that problem, a *Public School Version of the AAMD Adaptive Behavior Scale* has been made available (Lambert, Windmiller & Figueroa, 1974), but whether any predefined sequence of items for the severely handicapped person is appropriate remains a matter of debate.

In lieu of more traditional strategies, the selection of goals and objectives may be based upon the "criterion of ultimate functioning." That is, the relative importance of various skill development alternatives can be examined with respect to their implications for the individual's ability to function independently within current environments and/or desireable future environments (Brown, Nietupski, & Hamre-Nietupski, 1976). The ability to feed oneself is probably important in any environment; the ability to select foods according to a well balanced diet might be considered important if an individual was being prepared for placement in a situation where self-selection or preparation of meals was expected. That seems reasonable, but the extension of that logic to smaller units of behavior often causes difficulty. For example, Sailor and Haring (1978) suggest that the instructional target of "relaxing fingers" might be justified as one part of a three-part chain (grasp, raise and release) which in turn could lead to self-feeding and a "variety of other manipulative skills" (pg. 16). That, too, seems reasonable, but what if the child is motorically impaired and work over the last two years has not produced functional fine motor skills? Does one continue to work toward the approximation of normal physical movements, or shift to teaching the use of prosthetic devices which will enable self-feeding without normal hand movement skills? In that isolated instance, one could probably find time to work with both. When faced with similar problems in the development of functional skills in several different areas, the luxury of pursuing parallel courses of action might not be possible. Guidelines for assessing the functional relevance of various skills and choosing instructional targets have been proposed (cf., White, 1980c), but they still leave much to the creativity of the assessor and IEP team.

In summary, while there should be little difficulty in locating assessment instruments which have been developed specifically for use with severely handicapped individuals, there is likely to be a need to adapt specific assessment procedures and/or to add special items or item sequences to account for various handicapping conditions. Considerable difficulty can also be encountered in at least some cases when trying to decide which specific skill development needs should be addressed as goals or objectives. One should consider the specific environmental expectancies of an individual's current and projected placements, but the guidelines provided by most instruments for making such decisions are based upon traditional and inappropriate concepts of "typical" or "normal" developmental needs. While some scales do provide general guidelines for adaptations and/or adaptive skill development sequences, much is left to the judgement and inventiveness of the tester; and although procedures are evolving for evaluating the relative importance of various developmental needs in terms of the "criterion of ultimate functioning," those efforts generally amount to tentative first steps in what appears to be a promising direction.

Planning and Evaluating Daily Programs

IEP goals and intermediate objectives provide direction for an individual's program, but they do not provide sufficient detail for deciding how daily instruction or therapy should proceed. Two issues need to be addressed: (1) where and how instruction or therapy should begin with respect to each objective; and (2) how individual progress toward each objective will be monitored to decide if, when and how programs should be changed to facilitate continued progress.

Deciding Where and How to Begin The most common method for deciding precisely where instruction should begin is to extend the basic strategies used for developing the IEP to a more detailed level of analysis. For example, IEP assessments might determine that an individual needed to develop self-help skills in the area of dressing and, specifically, the skill of putting on shirts and blouses. The teacher would then conduct more detailed assessments to determine which specific steps needed to be taught (e.g., picking up shirt, placing arms through shirt, buttoning shirt) and which basic tool skills needed to be refined to facilitate the development of the self-help skill (e.g., fine-motor skills or the use of prosthetic devices). In the course of those assessments the teacher could also employ strategies to identify factors which should be considered in the selection of instructional procedures, like the natural cues and reinforcers which must eventually control the behavior, the cues and reinforcers which are most likely to prove effective during initial instruction, preferred sensory modalities and response types, and the major parts of the instructional plan which are most likely to be critical at the individual's current level of skill development.

Several IEP-level assessment instruments are specifically designed to facilitate those more detailed analyses. The *Pennsylvania Training Model Individual Assessment Guide* (Somerton-Fair & Turner, 1979) provides "profile" items for identifying major needs and detailed "taxonomy" items for identifying subskill development needs within major areas (e.g., dressing is divided into 43 subskills). Guidelines are then suggested for developing individualized task analyses and writing prescriptive teaching plans. Another IEP-level assessment instrument, the *West Virginia Assessment and Tracking System* (Cone, 1978), provides 576 items in 20 domains for preliminary assessment, and then cross-references those items to more than 5200 possible instructional steps and plans.

In cases where initial assessment instruments do not provide sufficient guidance for instructional planning, there are several curriculum guides developed specifically for use with the severely handicapped student. The *Teaching Research Curriculum for Moderately and Severely Handicapped* (Fredericks, Riggs, Furey, Grove, Moore, McDonnell, Gordon, Hanson, Baldwin, & Wadlow, 1976) provides two volumes of material devoted to task analyses of self-help, cognitive, gross motor and fine motor skills. Each of those skill sequences is accompanied by a statement of what is considered to be an appropriate terminal objective, a list of prerequisite skills, suggested materials and procedures for instruction, and references to the developmental sequence in which the various skills are usually mastered. The Cajon Valley Union School District in San Diego offers another compendium of potentially useful instructional sequences—*STEP: Sequential Tasks for Educational Planning* (1978). Most of the *STEP* sequences represent breakdowns or alternatives for the items on the *Behavioral Characteristics Progression* (Santa Cruz County, Office of Education, 1973), and the *BCP* already offers more than 2,400 items in 59 different skill areas In other words, many of the sequences provided by available curricula are detailed. Unfortunately, detail alone is not always sufficient.

Standard task sequences, no matter how detailed, may overlook the specific needs of a given individual. As finer and finer skill development needs are considered, probabilities increase that an individualized approach will be required to adequately define and meet those needs. Standard curricula and task analyses may provide some useful information for formulating individual assessment and instructional plans, but only if the probable advisability of deviating from those standard sequences and procedures is clearly understood. Program managers must have the skills to develop completely individualized approaches as the need arises (Sailor & Guess, 1983; also see Brinker, this volume).

Deciding If, When and How to Modify an Instructional Program Special educators agree that no matter how carefully an instructional program is designed, success can never be guaranteed. Even if a program is initially successful, it may lose its effectiveness as the needs and abilities of the learner change. Almost universally, therefore, special educators recommend the frequent evaluation of individual progress to determine if, when and how instructional programs should be modified.

Virtually all recommended evaluation systems are based on some direct measurement of an individual's attempts to demonstrate the skill in question. Most systems classify an individual's attempts on any given trial as "successful" or "unsuccessful" with respect to some preset criterion, but systems for recording other aspects of an individual's performance on any given trial have also been developed. One might, for example, record how long it takes an individual to begin responding (latency) or how long the individual takes to complete a response (duration). In situations where an individual does not respond independently to natural occurring stimuli, one might also record the "level of assistance" required to produce the desired response (Van Etten, Arkell & Van Etten, 1980), but some educators have rejected the use of such data as being too cumbersome and subjective (cf., Sailor & Guess, 1983).

Two major approaches are common for the organization and analysis of data after being collected. The first approach involves the notation of the specific sequence of outcomes on a trial-by-trial basis throughout the assessment period. Instructional decisions are then based on the pattern of successes and failures observed. For example, the criterion for moving to a higher level of instruction might be three consecutive successful trials. Such systems are most common in situations where the task to be learned has been divided into a series of steps, with each step small enough to be mastered within a single session. If acquisition of a single step is expected to take much longer than a single session, the pattern of sequential successes and failures is likely to become too complex for the analysis of overall learning patterns. Also, such systems are generally designed for serial instruction (i.e., instruction for one step of the task at a time) and are cumbersome for the concurrent evaluation of instruction provided for more than one part of a task at a time. Despite those limitations, systems for the trial-by-trial analysis of performance patterns are fairly common, especially as adjuncts to commercially available curricula (cf., Cone, 1978).

The second major approach for evaluating the progress of an individual is based on session-by-session summaries of performance. Rather than noting the specific sequence of correct and error responses within a session, simple totals are calculated for each session, and instructional decisions are based on the pattern of change observed for those totals across successive sessions. The behavioral counts are often transformed into percents (to reflect the overall accuracy of responding) or rates (to reflect both the accuracy and fluency of responding); and charts or graphs are used to facilitate the analysis of overall trends and patterns in the learning process. Session-by-session systems of progress analysis do not lend themselves well to within-session decisions (e.g., moving on after three successful trials); but they are more readily adapted to a wide range of curricula, instructional procedures and assessment situations. Some educators attempt to capitalize on the advantages of both systems by tracking the sequence of specific responses within sessions and overall levels of performance across sessions (cf., Cone, 1978). Most systems are based on only one approach or the other, however, with the cross-session analysis of overall performances being the most common.

The technology for making precise, timely and appropriate educational decisions based on the evaluation of an individual's daily progress is surprisingly advanced. Prior to 1970, most analyses of progress were based on the simple rule that if an individual appeared to be getting better, the program should be left alone; if not, then something should be changed. Obviously, such general rules were open to a wide range of interpretations. In the early-to-mid 1970's more specific rules began to emerge for deciding precisely when progress was no longer acceptable and the program needed to be changed. Rules have since been expanded to allow the analysis of an individual's pattern of performance in a manner which suggests when a program should be changed and which specific types of changes are most likely to be successful (cf., Haring, Liberty & White, 1980; White & Haring, 1982; Deno & Mirkin, 1977; Moore, 1982). Many of those systems have been validated in terms of their impact on the learning process. That is, it has been shown that handicapped individuals tend to learn faster when instructional decisions are based on specific rules than when they are not.

The evolution of more precise methods for the systematic utilization of ongoing performance measures is encouraging. Many of the difficulties encountered in the initial design of an individual's program can be corrected once the program is implemented. Still, it would be premature to say that all ongoing instructional decision issues have been resolved. The rules currently available tend to rely on specific data types and not all instructional approaches readily facilitate the collection of such data. Also, while rules exist for making decisions concerning initial skill acquisition and fluency building (i.e., bringing the fluency of a skill to a level where it becomes functional and useful), specific rules for making performance-based decisions about when and how one might facilitate skill generalization and adaptation have not been validated.

Overall Program Evaluation

Evaluation issues and systems discussed thus far have focused on the process of deciding how best to meet an individual's needs. That should be the primary concern of any educational system. Many educational decisions will affect more than a single individual, however. Decisions must be made about staffing patterns, facilities, the purchase of materials and equipment, inservice training and the adoption of "educational models," just to name a few. Such generic, system-level decisions require what is called "program evaluation."

Appropriately, there is a reluctance on the part of evaluators to recommend a single approach to program evaluation. Different programs will be developed to serve different needs and should be evaluated using different strategies. Still, the need to identify effective educational models is great, so in 1973 the U.S. Office of Education established the Joint Dissemination Review Panel to facilitate that process. The purpose of the panel is not to dictate specific evaluative procedures, but rather to review whatever evaluation procedures a federally funded program chooses to employ. If the evaluation is deemed to be scientifically valid and demonstrates educationally significant effect, then the program is "validated," listed in an annual publication called "Programs That Work," and allowed to disseminate program information with the "federal seal of approval."

Acceptable methodologies for the evaluation of federally funded development programs remain "officially" undefined, but the Joint Dissemination Review Panel has become increasingly more "suggestive" concerning the approaches which it is most likely to consider valid. Specifically, the JDRP's "Ideabook" (Tallmadge, 1977) suggests only three references for evaluation designs (Horst, Tallmadge & Wood, 1975; Tallmadge & Horst, 1976; Campbell & Stanley, 1963). All three of those sources emphasize the use of traditional "large-n, group-oriented" program evaluation strategies—the study of large groups to determine how the group as a whole reacts to a program. Three types of evaluation designs in particular have been recommended by JDRP-related publications: equivalent group comparisons, covariance or regression analyses, and norm-referenced analyses.

Traditional Group-Oriented Evaluations In an equivalent group evaluation two or more groups of similar students are formed. One of the groups is provided the program being evaluated; the others are provided alternate programs or, possibly, no program. Usually two measures are taken—one before the programs are started (the "pretest") and one after the programs have been completed (the "posttest"). If the group exposed to the target program performs better than the other groups, the program is considered effective. It is important that all groups be essentially the same to make the comparisons valid. Ideally, that similarity is assured by randomly assigning children to each group, but special "matching" procedures can be employed (Tallmadge & Horst, 1976).

If two or more directly equivalent groups cannot be formed, statistical analyses can be employed to artificially adjust for initial differences (analyses of covariance or regression). In order for statistical adjustment models to be meaningful, however, the groups must differ only by degree, not kind. Statistical adjustments might be acceptable if one group simply scores a bit lower on the pretest than another group, but no amount of statistical adjustment would make a group of deaf-blind students comparable to a group of seeing/hearing children (White, 1980b).

Finally, if no direct control group is possible, the performance of students in a program can be compared to previously established norms or expectancies. In essence, the group of students used to norm a test becomes the "control group." If the students in the program increase in standing relative to the original norming sample (e.g., move up in percentile rank), then the program is judged more effective than whatever programs those other students attended. Of course, the comparison is only valid if the norming group is like the one involved in the program being evaluated (Horst, Tallmadge & Wood, 1975).

The procedures outlined above share many characteristics in common. Little information is collected concerning any single individual, so little can be said with confidence about the way in which individual students react to the program. Estimates of program impact are based on the uniformity of effect demonstrated by the group as a whole. If all children in the program group progressed more rapidly than all the children in an equivalent control group, one might state with confidence that the program had a reliable effect. Of course, individual students are likely to react differently to a program, so one group will not usually have uniformly better performances than the other. Most group-oriented approaches are then forced to rely on special statistical procedures to determine whether the students exposed to the program are performing better than other students "on the average." The ability of statistical tests to identify believable differences among groups depends upon the number of students studied (i.e., larger groups allow smaller differences to be detected) and the variability within each group (i.e., if students are similar in terms of performance or rate of progress, it is easier to determine how the group as a whole reacted to the program). Unfortunately, those characteristics of group-oriented evaluations make it inadvisable to employ such designs with programs serving severely handicapped populations.

As should be apparent from earlier discussions, severely mentally retarded individuals can display a tremendous range of characteristics. To account for those differences would require large groups, but since the severely handicapped group represent a small proportion of the general population, programs do not have access to the number of students required for a reasonable "equivalent group" approach. Moreover, since differences among the severely handicapped are as often a matter of kind rather than degree (e.g., sensory impairment versus no sensory impairment), statistical adjustments for initial group differences are generally impossible. Finally, the concept of a "norm" or "typical expectancy" for the severely handicapped is inappropriate. At least at this point in time, one cannot say what the "typical" severely handicapped individual can be expected to achieve.

Individually-Oriented Evaluations Fortunately, there is an alternative to the group-oriented approach. Instead of using estimates of group reactions to evaluate program impact, the progress records of individual students can be studied. As with group approaches, there are several different specific evaluation designs one might employ (cf., Hersen & Barlow, 1976; Kratochwill, 1978; Johnston & Pennypacker, 1980; Horn & Heerboth, 1982), but most designs monitor individual students on a regular basis through periods when they are involved in the program being evaluated and through other periods when they are not involved in that program.[1] If levels of performance or rates of progress are consistently better during program involvement, the program is judged effective. Of primary concern is the fact that individual characteristics and differences are not "lost in the average" and, since each individual is exposed to both program and nonprogram conditions, they can serve as their own "controls," obviating the problem of finding other students that can serve as appropriate matches.

Individual evaluations conducted over a reasonable period can prove as powerful and persuasive as larger group approaches in detecting program impact. Indeed, the types of program impact detected by the individual approach can be more meaningful than those usually studied with group-oriented approaches. The group approach attempts to summarize the "average" impact of a program; but that "average" is likely to be significantly less than realized with some students, and more than realized with others. With the individual approach to evaluation, the magnitude of program impact can be determined for each student. If some students benefit from the program and others do not, those differences are made clear, rather than buried in an overall average. Also, since individual evaluations are based on a series of assessments in each program condition, one can determine if most of the gains are made early in the program, steadily throughout the program, or whether gains are only achieved after a long period of adaptation to the program—information valuable in deciding how long a program should be employed to realize desired benefits.

Finally, the typical group-oriented evaluation attempts to build a logical case for generality of effect on the basis of the similarity between the group of students evaluated and some other broader population of students. That is, if one wished to say that a program will work with "severely mentally retarded, physically intact" students, then one would try to evaluate the program on a "representative sample" of such students. Forming representative samples is, of course, no easier than forming matched control groups. It can actually be far more difficult, since few programs have the luxury of "randomly sampling" the students they will serve from some broader population; nor are programs usually in a position to say unequivocably that the students they serve are, as a group, similar to the students served by other programs interested in adopting the same educational model. With individual evaluations, each student serves as a self-contained, complete study of program impact; and each repetition of the evaluation on a different student provides a direct measure of the degree to which similar program effects can be expected with different types of students.

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[1] Formally, individually-oriented evaluations are called "single-subject," "single-case" or "time-series" evaluations. The first two names come from the fact that only one person (student) needs to be involved; the "time-series" label comes from the fact that a series of assessments are conducted over time.

Individually oriented evaluations are not without possible fault, of course. Like all evaluations, they must be designed and conducted with care to avoid problems which might make the results difficult or impossible to interpret (White, 1984). Since many assessments are required for each individual, they tend to be more time consuming and expensive than group-oriented strategies (Horn & Heerboth, 1982); and each student must be exposed at least briefly to "nonprogram" conditions which might raise certain ethical concerns; albeit, not any more than would the assignment of an entire group of students to some "control" condition for a longer period (White, 1980b). Individual evaluations also tend to focus on the continuous assessment of only one or two instructional programs for each student, so there may be some difficulty in establishing the degree to which those programs represent the individual's "overall development" (White, 1980b). Still, individually-oriented approaches do generally represent the method of choice when evaluating programs serving the severely handicapped (White, 1984).

ANTICIPATED TRENDS

It is difficult to predict the course which the development and practice of special education evaluation will take in coming years. Practices are too often shaped by shifts in general societal attitudes or by the intuitive genius of a dedicated educator. Nevertheless, there do appear to be three major trends.

Individualization While severely mentally retarded people were initially considered as "individuals" only in the sense that they were "misfits" with respect to the general population, the level of individualization possible today is almost overwhelming. Not only is one child considered different from other children, a single child's needs are considered to be potentially different in each area of development, from one instructional program to another, and even from one day to the next. The amount of information and level of detail processed during initial evaluations and ongoing instruction is actually reaching a point where it may interfere with the ability of decision makers to reach timely and effective conclusions. There would seem to be a need to temper concern for the identification of individual characteristics with a system for deciding which characteristics are most important for making various decisions. That system seems to be evolving as a result of the other major trends discussed below.

Functionality One of the most promising and exciting trends in the evaluation and education of severely handicapped persons is the increasing concern for "function." Rather than continuing with the historical focus on what might be "normal" or following some "standard curriculum," educators are beginning to assess critical environments to determine which skills are or will be most important for independent functioning. When typical forms of behavior cannot be developed to achieve certain ends, functional alternatives are systematically investigated. The need remains to develop a system for placing various needs into some perspective, however. While it is relatively simple to identify current critical environments (e.g., home, community, school), potentially relevant future environments are not always evident, especially for the young child. Extensive analyses must be completed concerning the eventual functional implications of various skills, both in isolation and as parts of interrelated sequences of skill development.

Decisions As mentioned at the beginning of this chapter, evaluation is a process through which *action-oriented decisions* are made. Labeling a new born infant as "Down syndrome" is not evaluation, no matter how precise and elaborate the diagnostic procedures may appear to be. Deciding on the basis of that information to enroll the infant in a program designed to foster development *is* evaluation. Similarly, assessing a child's daily progress through an instructional sequence is not evaluation. Nor does it become evaluation when at the end of the year a report is written to indicate how many programs were successful. That report might be valuable to other decision makers in formulating the next IEP, but the daily progress data itself can only be considered an act of evaluation when that information is used to make explicit decisions about when and how the program should be improved. While some might be content to simply count and chart a pupil's behavior, many educators appear to be developing a keener sense for the meaning behind it all—the need to make decisions which actually help pupils to achieve what they are capable of achieving. As long as that trend toward a concern for decisions maintains, it should continue to enhance the development of ever more effective evaluation strategies.

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CHAPTER 10/

INTEGRATION EFFORTS FOR STUDENTS WITH SEVERE MENTAL RETARDATION

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P.L. 94-142
Recent research and program development efforts
Child-centered interventions
Interventions with preschool children
Interventions with elementary-age children
Interventions with secondary-age children
Environment-centered research
The Brinker study
The Voeltz studies
The socialization research project
Toward a theory of social competence
Social competence in integrated settings
Social competence
Social perception
Social interaction
Implications for research and policy development
Social integration policy
Research needs
Summary
Reference notes
References

A recent segment of *Good Morning America* included a report regarding the closing of a small elementary school in a middle class suburb in Southern

California. The action was the subject of a particularly prolonged and vigorous series of protests by parents of the children involved. What distinguished this school closing from a myriad of others in the present era of decreasing enrollment was not the distance students would have to travel to a new school (which was only a few blocks away), the inferiority of the new school program, nor the threat of crowded classrooms and overloaded teachers. The central issue protested in this school closing was the disruption of regular contact between the elementary school children and peers enrolled in a special education program for children with severe and multiple handicaps. Significantly, it was the parents of the *nonhandicapped* children, many of whom regularly participated as peer tutors or social companions to the disabled children, who protested the closing of the school most vehemently.

Until the late 1970s, the types of social and educational experiences which motivated these parents to protest the separation of severely handicapped and nonhandicapped school children were not available in public schools in the United States. Indeed, programs which seek to integrate children with severe handicaps into regular school life are just beginning to become common. The existence of programs like the one described above, as well as other integrated school programs from the preschool to secondary levels, are the result of a complex and dynamic set of social-political and educational changes which have taken place over the last few decades.

An important change was reflected in a national right to education movement for moderately and severely handicapped children—who were routinely excluded from school services before the 60s. Fundamentally a parent-initiated campaign, the right to education movement gained professional attention and support and became infused with the egalitarian values of the civil rights era. Thus, the relevance of the segregation issue to special education did not gain widespread attention until the late 60s. On the contrary, the assumption in special education had been that the segregation of handicapped children served a protective and educational function (MacMillan, 1977), even though research directed toward testing this assumption had not produced convincing results (Kirk, 1964; Guskin & Spicker, 1968).

Two relatively new views on special education were advanced in the late 60s which transformed the segregation issue and the related practice of "mainstreaming" into the most hotly contested special education policy debate of the 70s. The first view was articulated in a 1968 paper by Lloyd Dunn entitled "Special Education for the Mildly Retarded—Is Much of It Justifiable?". His argument shifted the "burden of proof" onto special education to show that the potential harms resulting from labeling and segregating children, as well as the extra expense of special classes, could be justified by the superior gains in achievement and adjustment for handicapped students. Since then reviews of empirical evidence related to the efficacy of special education consistently indicate that segregated special education has not convincingly demonstrated its superiority to regular classroom arrangements (Semmel, Gottlieb, & Robinson, 1979; Strain & Kerr, 1981).

The second major viewpoint which accelerated parental and professional concern with the effects of segregation was expressed in the human services philosophy of normalization introduced to this country by Nirje (1969) and most comprehensively articulated by Wolfsenberger (1972). The goal of the normalization movement has been to assure that individuals with disabilities enjoy patterns of life and everyday experiences similar to those of most citizens (Nirje, 1969).

P.L. 94-142

Both the right-to-education movement and the normalization philosophy shaped central provisions of landmark federal legislation passed in 1975: Public Law 94-142. P.L. 94-142 recognized the right of all handicapped children to receive a free and appropriate public education, regardless of the severity of any disability. The integration philosophy expressed in the normalization principle was reflected in a mandate that handicapped children be educated, "to the maximum extent appropriate," with children who are nonhandicapped. While the practice of maximizing the integration of handicapped children into regular public schools became official federal policy with P.L. 94-142, de facto separation and isolation of children with severe handicaps is still the reality in all but a few districts across the nation (Stetson, 1979).

RECENT RESEARCH AND PROGRAM DEVELOPMENT EFFORTS

Research and development efforts related to the social integration of severely handicapped children in public school settings have typically focused on evaluation of interventions aimed at increasing the quantity and quality of cross-group social integration. This is in contrast to the predominant focus of the research literature on integration of mildly handicapped learners, which has usually involved comparing outcomes of integrated and segregated classrooms (see Semmel, Gottlieb, & Robinson, 1979, for a review). A number of researchers have noted that pervasive problems with a) experimental design, b) specification of independent variables defining integration, segregation, or mainstreaming, c) the reliability and validity of measurement and, d) representativeness of research samples prognosticate poorly for future efforts to tease out differences in outcomes associated with integrated or segregated services (MacMillan & Semmel, 1977; Peck

& Cooke, 1983; Strain & Kerr, 1981). Additionally, Peck and Cooke (1983) have argued that much of the effort to bring an empirical orientation to the issue of educational segregation has represented an inappropriate confusion of philosophical and empirical questions. Thus, the question of whether integration is an appropriate societal goal may be viewed as predominantly philosophical in nature. An affirmative answer to that question (as expressed in the 1954 Brown desegregation decision and P.L. 94-142) suggests that empirical inquiry should be focused on *how* to best achieve the goals of social integration.

The intervention research on the integration of children with severe handicaps may be considered in terms of attempts to modify both child and environmental characteristics. This is consistent with formulations from the fields of ecological, behavioral, and personality psychology (Bandura, 1977; Barker, 1966; Lewin, 1951; Mischel, 1968) which conceptualize behavioral adaptation as a function of both personal and environmental factors [B = f(P,E)]. While recognizing the actual interrelating and transactional nature of child and environment characteristics, we will distinguish intervention efforts aimed directly at child behavior change from those directed toward achieving more global environmental or system changes.

Child-Centered Interventions

A consistent finding from direct observational investigations of social integration efforts has been that placing handicapped and nonhandicapped children in the same classroom environment is not likely to produce cross group social interaction (Ballard et al., 1977; Cooke, Cooke, & Apolloni, 1978; Peck, Apolloni, Cooke, & Raver, 1978; Guralnick, 1976). Indeed, there is some evidence that, in the absence of specific intervention, interaction between children with moderate or severe handicaps and nonhandicapped peers may *decrease* over time (Guralnick, 1980, 1981a; Sinson & Wetherick, 1981). Thus, the need for specific programmatic intervention aimed at maximizing the social integration of handicapped and nonhandicapped children has been recognized for sometime now (Snyder, Apolloni, & Cooke, 1977).

Interventions with Preschool Children

A relatively large portion of social integration research directed at the preschool level have been descriptive in nature (Peck & Cooke, 1983). These studies have typically found that mildly handicapped children are relatively well integrated with nonhandicapped peers, while children with increasingly severe handicaps tend to be more isolated (Guralnick, 1980, 1981a; Ispa & Matz, 1978; Sinson & Wetherick, 1981). While these studies provide useful descriptive information, they underscore the need for intervention research directed at improving social integration outcomes for severely handicapped children.

Some successful interventions have been reported which have involved direct teacher modeling and reinforcement of social play between handicapped and nonhandicapped children. For example, Fredericks et al. (1978) described the use of these techniques with six moderately and severely handicapped children in an integrated preschool. They reported increases in cross group social play when teachers modelled and reinforced social interaction in naturally occurring play situations. Although these findings suggest the potential value of their intervention package, the need for its replication is equally clear in view of the correlational nature of the data they report (their design was an AB with no demonstration of experimental control). Other research (Shores, Hester, & Strain, 1976) has indicated that direct teacher intervention in ongoing play interactions between preschool children may have disruptive and decelerating effects on child-child interaction. Research is needed toward delineation of the conditions which may predict the success or failure of the types of teacher-mediated interventions suggested by Fredericks et al. (1978).

Another intervention approach has been pursued with preschool-age children by Cooke and Apolloni, and their colleagues (Apolloni, Cooke, & Cooke, 1977). These investigators have attempted to directly teach handicapped children to imitate nonhandicapped peers: a critical social skill which would likely facilitate further learning and social interaction. An initial investigation was carried out in a highly structured setting with three moderately retarded children and one nonhandicapped peer. Extensive adult prompting and reinforcement techniques were used to increase the handicapped child's imitation of the appropriate materials-use behaviors of the peer model. Some generalization of training effects to a post training situation and to nontrained responses was observed. Similar results were obtained in a subsequent experiment focused on imitation of verbal responses modeled by a nonhandicapped peer. Results of both of these experiments indicated that the Peer Imitation Training did not substantially improve the children's behavior in more naturalistic, free-play settings. Consequently, a third investigation was carried out (Peck, Cooke, Apolloni, & Raver, 1978) which followed suggestions from the generalization literature that training be implemented directly in the natural environment (Stokes & Baer, 1977). Results were more positive. The five children with moderate levels of mental retardation who participated in two experiments described in the study demonstrated increases in peer imitation in both training and naturalistic generalization environments. Concomitant increases were observed in general social interaction between the handicapped children and nonhandicapped peers.

A third approach to increasing social interaction between nonhandicapped and severely handicapped preschool children has involved peer mediated interventions (Strain, Kerr, & Ragland, 1981). Strain and his colleagues have conducted an extensive line of investigations on the use of peer initiations as a means of increasing social interaction between handicapped and nonhandicapped children. In an early study, Strain, Shores, and Timm (1977) taught specific verbal and gestural social interaction skills to nonhandicapped children for use with severely handicapped peers. Increases in initiations by nonhandicapped peers were associated with increased social responses and initiations by the handicapped children. This technique was later replicated with moderately retarded children, and effects were observed to generalize across setting and maintain through a next day follow-up (Strain, 1977).

Ragland, Kerr, and Strain (1978) then attempted peer initiation procedures with children diagnosed as autistic. The subjects in this investigation also demonstrated increases in positive social behavior with the nonhandicapped peer when the peer initiation technique was implemented. However, Ragland et al. also observed increases in the autistic childrens' negative affective behaviors such as crying, screaming, or escape attempts when peers initiated interaction with them. Similar negative side-effects reported by Nordquist (1978) using a peer-mediated intervention strategy with an autistic child suggest that this population may continue to present unique challenges to interventionists even when some targeted behavior changes are achieved.

Further work by Strain and his associates has involved direct comparison of different peer-mediated intervention techniques (Strain, Kerr, & Ragland, 1979) and assessment of conditions facilitating generalization of behavior changes achieved with the peer initiation procedure (Strain, 1983). The Strain et al. (1979) study consisted of comparing the peer initiation technique to peer mediated direct prompting and reinforcement of social responses. Both procedures produced positive behavior change, and in comparable amounts. Neither procedure was associated with generalized behavior change.

In the later study, Strain (1983) carried out the peer initiation intervention with four "autistic-like" boys with varying degrees of moderate to severe mental retardation. The central question in this study was whether differential generalization effects would be associated with the integrated or segregated nature of the generalization environment—a recess time in the school gym. Results for all four subjects demonstrated that superior generalization of treatment gains was achieved in the integrated situation. These results offer some of the strongest empirical support to date for the functional effects of social integration on children's performance.

Interventions with Elementary-Age Children

Unfortunately, relatively little child change research has been conducted related to facilitating direct social interaction between severely handicapped and nonhandicapped children at the elementary-age level. A notable exception is a report by Russo and Koegel (1977). These authors described the use of behavioral techniques to integrate an autistic child into a regular elementary classroom. A package of behavior modification techniques was used to: a) improve the child's social behavior; b) reduce self stimulation behaviors; and c) increase her verbal responses to commands. The package was effective in changing each of the targeted behaviors, and the child was successfully mainstreamed in a kindergarten classroom where the program was implemented by the regular teacher. Unfortunately, the child's maladaptive behaviors returned to baseline levels when she was transferred to a first grade classroom. When the new teacher was trained to implement the program, the child recovered previous gains. The Russo and Koegel report currently represents the most carefully operationalized and empirically valid effort to integrate a severely handicapped child into a regular elementary classroom.

Interventions with Secondary-Age Children

A number of social integration efforts have been conducted with junior high school and high school students which have focused on changing the behavior of the handicapped or nonhandicapped students involved. These reports have usually been based on integration programs implemented in recreational settings. For example, Johnson et al. (1979) utilized a cooperative goal structuring strategy (Johnson & Johnson, 1975) to increase positive social interaction between nonhandicapped and moderately retarded junior high school students. Thirty students (12 handicapped and 18 nonhandicapped) were randomly assigned to bowling teams which differed by the goals which defined "winning." Cooperative teams were instructed to maximize the group's score, and to assist each other in improving their bowling skills. Individualistic conditions consisted of giving each student instructions to maximize his or her own score. A third group, labelled "laissez faire" received no special instructions. Results for both handicapped and nonhandicapped students indicated that the cooperative condition was associated with much higher levels of positive social interaction than either the individualistic or the laissez faire conditions. The study was replicated by Rynders, Johnson, Johnson, and Schmidt, (1980) with similar results. The Rynders et al. study extended earlier findings by revealing that higher sociometric ratings of handicapped bowlers by nonhandicapped teammates were obtained under the cooperative condition, and that praise and support from nonhandicapped students was higher for *both* handicapped and other nonhandicapped teammates under the cooperative goal structure. These results are most encouraging in light of the common assumption that the predictably subaverage performance of the handicapped students would be likely to negatively affect attitudes toward them. The consistency of supportive findings across populations (Johnson & Johnson, 1980) suggests that cooperative goal structuring may be a particularly fruitful strategy for promoting positive outcomes of integration experiences for handicapped and nonhandicapped children.

Santomier and Kopczuk (1981) reported results of pairing junior high-age nonhandicapped students with moderately handicapped agemates for a series of physical education periods conducted twice a week for 14 weeks. Experimental groups compared the effects of the pairing intervention with and without accompanying teacher praise for social interaction between handicapped and nonhandicapped students, and with a control group which received no specific interaction intervention. Analysis of the pre-posttest difference scores indicated that the group receiving the pairing and social praise package demonstrated significantly more positive interaction between handicapped and nonhandicapped students.

Similar programmatic objectives were pursued by Donder and Nietupski (1981). These authors developed a program of recreational integration involving three junior high school students with moderate mental retardation and 14 nonhandicapped peers. The nonhandicapped students volunteered to participate in two one-hour training sessions which prepared them to tutor the handicapped students in age-appropriate playground skills. The training sessions were followed up on the playground with feedback regarding use of basic teaching techniques. A multiple baseline across subjects design was employed to assess the effects of the program in establishing and maintaining positive social interaction between the handicapped students and their nonhandicapped peers. Baseline social behavior observations revealed high rates of inappropriate interaction for each subject. This pattern was dramatically altered with implementation of the intervention program, producing substantial and durable (at two weeks post-intervention) increases in positive cross-group social interaction.

Environment-Centered Research

Environment-centered research tends to be broader in scope and more diffuse in operationalization of the independent variable under investigation than does child-centered research. In addition, environment-centered research tends to be large scale involving the comparison of sizable groups of students under different educational conditions.

A typical environment-centered research question would be: what are the effects of integrated versus segregated settings upon students? The segregated setting might be a school or group of schools who have no severely handicapped students on their campus. The integrated setting might be a school that has at least one class of severely handicapped students on its campus. Immediately, it can be seen that the variable of integrated versus segregated is rather gross with respect to operational detail. For example, an integrated school could have one, two or more classes of students with severe handicaps. The number and proportion of severely handicapped students might vary considerably (e.g., 1–50 percent of the school). The class(es) might be centrally situated in the school building or they could be on the periphery of the campus. The special education program could be administered by the same school district as the regular school program or it might be run by a different administrative unit. These and other factors may lessen the degree of control of the independent variable when comparisons are made between integrated and segregated groups of students. Still, some investigators have taken precautions to operationalize their contrast groups with an impressive degree of specificity (cf., Voeltz, 1980, 1982, Note 1).

The Brinker Study

One large-scale study by Brinker (Note 2) made global contrasts of integrated and segregated programs. The most impressive characteristic of the study is its comprehensive sampling of 14 varied school districts across the United States. A total of 328 nonhandicapped students (age 5–18 years) were administered different forms of Voeltz's Acceptance Scale. A total of 158 students (83 female and 75 male) attended segregated public schools where there were no severely handicapped students present. A sample of 170 students (125 female and 45 male) attended integrated schools and were nominated by special education teachers at the school for having substantial amount of contact with their severely handicapped students. The two groups of students were matched according to grade level and schools of similar size and socioeconomic status. The scale was administered to all of the students in the Fall of 1981 (pretest) and in the Spring of 1982 (posttest).

The results showed significantly more positive attitudes toward handicapped persons (total Acceptance Scale score) for the integrated (versus segregated) students in the third through twelfth grades. There were no differences between groups in the kindergarten through second grades. In addition, there were no changes from pretest to posttest. Finally, there were significant sex differences across all grades with females having more accepting attitudes than males. Thus, positive effects of integration in leading to more positive attitudes toward handicapped persons were apparent from this large scale study.

The Voeltz Studies

The studies by Voeltz (1980, 1982, Note 1) further partitioned the independent variable into the types of contact possible at an integrated school. The Brinker attitude study had contrasted nonhandicapped students at segregated sites with nonhandicapped students nominated by special education teachers as having had considerable contact with severely handicapped students. The Voeltz research took another direction. She had three groups comprising the independent variable. All of the students were in the fourth through sixth grades. One sample of students attended schools where there were no severely handicapped students (no contact). Another sample of nonhandicapped students attended integrated schools without a systematic program to facilitate interaction between severely handicapped and nonhandicapped students (low contact). A third sample of students (high contact) attended integrated schools where a systematic program was in effect to promote positive interactions and attitudes between nonhandicapped and severely handicapped students. The program had two components. Students at the schools received a slide/sound presentation describing severely handicapped students enrolled at that school, followed by a brief question and answer period. Next, about half of the students in the school participated in a "special friends" program.

The Acceptance Scale was administered to all students at each of the schools (Voeltz, Note 1). There were two schools in the "no contact" sample (n = 288), two schools in the "low contact" sample (n = 330), and one school in the "high contact" sample (n = 254). The first administration of the scale, in the Fall 1978, occurred after the low and high contact schools had experienced a year of integration and the high contact school had undergone a semester of the systematic program. The high contact group was found to have higher acceptance scores than the low contact group, which had higher scores than the no contact group. These differences may reflect the benefits of social integration. The Fall scores also support the benefits of the systematic programming over no programming in integrated sites.

Taken as a whole, the work by Voeltz (1980, 1982, Note 1) represents our most comprehensive body of knowledge describing the positive effects of school-wide integration and systematic programming. The series of studies used large samples, were longitudinal, built in meaningful contrast groups and used elegant statistical analyses. On the negative side, there was not random assignment to the experimental groups; although randomization procedures are not likely to be found in large-scale evaluation research because of practical and logistical problems. There was no true pretest so there is uncertainty about the equivalence of the experimental groups before integration took place. In addition, there were demographic differences between the groups in that the low contact schools were urban, the no contact schools were rural and suburban, and the high contact school was suburban (although achievement score data indicated the equivalence of the students in reading and math achievement across the five schools; Voeltz, 1982, Table 1). Finally, there is a concern that the high contact findings were obtained at one school. Notably, the findings of the Brinker investigation, which were collected across a wide variety of school districts, generally support the results of the Voeltz studies.

The Socialization Research Project

A third group of investigators (Haring, Breen, Pitts-Conway, Lee, & Gaylord-Ross, Note 3) have examined the behavior of nonhandicapped adolescents toward handicapped students. The data for the project are still being collected but preliminary findings on 25 students are reported here. The study was conducted at a single secondary site in a suburban public high school in California. The school had one severely handicapped class and two other special education classes on the campus.

The independent variable partitioned three groups of 10th–12th grade students. There was no segregated (no contact) group since all of the students attended a school where there was a class of severely handicapped students. However, a control group was constructed of students who volunteered for the interaction program with the severely handicapped class but were not selected to participate that semester. In the clinical research literature this would be referred to as a waiting list control group since these students did eventually participate in the interaction program, but not during the semester under study. The waiting list control group design has an advantage over other kinds of control groups because the waiting and treatment groups have expressed similar interests and commitment in becoming involved with the treatment.

The Socialization Research Project study allowed students to select two types of social interaction programs. A Peer Tutoring Program had students come to the special education class for one 45-minute period per day, five days per week, for a 4½ month semester (September through January or February through June). During the period the peer tutor would teach the handicapped student some tasks from the latter's IEP. The peer tutors were taught the rudiments of systematic instruction (Snell, 1978).

A second group of students enrolled in a Special Friends program. The Special Friends group of nonhandicapped students met for the same time segments as the peer tutors, although some of their interaction was conducted outside of the special education classroom. The Special Friends program consisted of pairing a severely handicapped student with a nonhandicapped student to participate in social/leisure activities. They were instructed to "play" together and no tutorial role was designated for the nonhandicapped student. The nonhandicapped student was not taught or expected to use the methods of systematic instruction. Some of the social/leisure activities which the special friends engaged in were tennis, video games, and checkers.

The dependent variable in the study was a "behavioral probe" where a nonhandicapped student came to a room and was told to wait to be interviewed. Another person sat across from the waiting student. The waiting period lasted five minutes. The nonhandicapped student (in separate sessions) was exposed to three different kinds of persons while waiting. One individual was an unfamiliar autistic person. A second person was a familiar autistic youth. The third person was an unfamiliar nonhandicapped person. All of the waiting persons were male and between the ages of 18 and 25. An unobtrusive observer sat in the corner of the room and recorded the duration of social interactions between the two individuals. The waiting confederate never initiated an interaction and made minimal social responses to the nonhandicapped student under investigation.

All of the participants were probed before the beginning of the intervention (pretest) and were posttested after the completion of the Special Friends and Peer Tutoring programs. The control group essentially emitted no interactions. The social interaction groups were basically noninteractive during the pretest probe. Upon posttesting, though, a number of interesting trends emerged. First, there was zero interaction with the unfamiliar nonhandicapped person. Second, there was a sizeable increase in interaction with the unfamiliar autistic person for both special friends and peer tutors. Third, there was even greater interaction with the familiar autistic peer, with the Special Friends group having a much longer duration of interaction than the peer tutors.

The behavioral probe data indicate that interaction programs do appear to lead to the development of social skills among nonhandicapped adolescents toward their autistic peers. There is a proclivity to interact longer with familiar autistic persons and this effect seems more pronounced when the student has participated in a special friends rather than a peer tutoring program. These results thus provide some preliminary support to Voeltz's contention that special friends is a preferred interaction program to peer tutoring. More importantly, the findings support the earlier work by Brinker and Voeltz suggesting that integrated school settings which promote social interaction tend to produce positive behavioral and attitudinal development among nonhandicapped students toward their severely handicapped peers.

Toward a Theory of Social Competence

Given the burgeoning research and policy interest in educational integration, it would be helpful to formulate a model or theory which articulates relationships between integration experiences and social development among severely handicapped individuals. Such a model would help synthesize past empirical findings and guide future research and program development efforts.

The polemics with the controversy of integration versus segregation have a historical parallel in the nature versus nurture controversy regarding the bases of human intelligence. The nature-nurture question was originally posed as whether intelligence was determined completely by one's native endowment or by the external environment. As the science of psychometrics and behavioral genetics evolved, certain investigators (e.g., Jensen, 1969) quantified the relative contributions of environment and heredity to intelligence in terms of an additive formula. In this formula, biological factors accounted for 80 percent of an individual's intelligence. The either-or and additive approaches to explaining intelligence were rejected by Hirsch (1975), an eminent behavioral geneticist. Hirsch described an alternative conceptualization, a range of reaction notion which had been developed with nonhuman species. The range of reaction model postulates that a given genetic trait may be expressed in multiple ways given environmental variety. Furthermore, the model states that one can never make a complete determination of an individual's intelligence (a trait) until the organism has been exposed to a wide variety of environments. Thus, there is not a singular or dual causality of intelligence, heredity and/or the environment. Rather, the genotype interacts with a multiplicity of environments to produce a composite portrayal of phenotypical intelligence.

The range of reaction notion has critical implications for educational programming of severely handicapped students. Figure 10.1 presents a scheme for the social integration of handicapped students which mirrors the range of reaction model. Here, the severely handicapped individual appears in the center of the fan. Moving out from the individual are different environments with which the person comes into contact, e.g., vocational, residential, community, school. The individual displays a variety of behaviors across these multiple environments.

With respect to the integration-segregation issue, integrated environments are likely to have more differentiated fans—that is, the individual may have substantial contact with many environments. Segregated settings, by definition, expose the person to fewer environments. Thus, integrated settings present a wide range of situational stimuli. The important point is that these represent opportunities for the individual to develop a rich repertoire of responses to these environmental demands. The highly differentiated environment induces the development of skills and behaviors that never would have been observed in less differentiated settings. Thus, the potential of the severely handicapped individual can only be accurately assessed after there has been substantial exposure to a variety of environments (Strain, 1983).

Social Competence in Integrated Settings

Let us further examine the types of environments and interactions that would occur in integrated and segregated settings. In the segregated secondary school there would be the special education classroom. Students are likely to spend a great proportion of their instructional day in the self-contained classroom. The school might also have a multi-purpose room for adaptive physical education and other sensorimotor activities. There

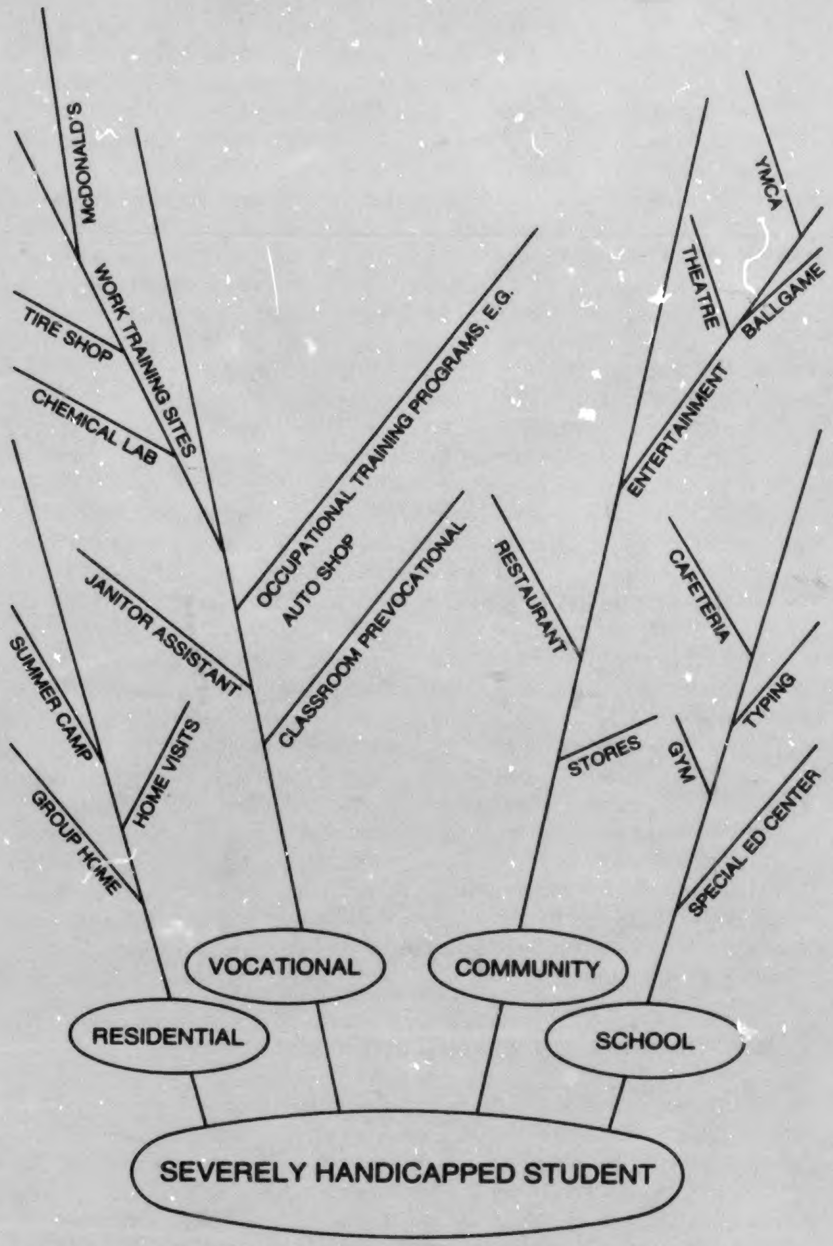
McDONALD'S
WORK TRAINING SITES
TIRE SHOP
CHEMICAL LAB
OCCUPATIONAL TRAINING PROGRAMS, E.G.
AUTO SHOP
JANITOR ASSISTANT
CLASSROOM PREVOCATIONAL
SUMMER CAMP
HOME VISITS
GROUP HOME
YMCA
THEATRE
BALLGAME
ENTERTAINMENT
RESTAURANT
CAFETERIA
TYPING
STORES
GYM
SPECIAL ED CENTER
VOCATIONAL
COMMUNITY
RESIDENTIAL
SCHOOL
SEVERELY HANDICAPPED STUDENT

Figure 10.1 Schematic of a differentiated, integrated environment.

may also be clinical offices for speech or occupational therapy. There is likely to be an outdoor playground for recess and there may be a cafeteria for lunch. The interactions occurring in these subenvironments are with adult staff or with handicapped peers.

In contrast, in the integrated secondary school setting there is a greater number of subenvironments. The large public high school is typically a vast resource of many academic, vocational, and recreational environments. The resourceful teacher of severely handicapped students can get his/her students involved in many program offerings. Through these normalizing experiences the student may become more socially competent in dealing with the surrounding world.

Social Competence

The integration of severely handicapped persons should not be viewed as an additive process where segregated and integrated settings produce increased effects upon the individual's functioning. Rather, a nonlinear, fan-shaped model was proposed which defined social competence in terms of the conglomerate of skills needed to perform in a range of varied environments. Thus, as the person is exposed and successfully adapts to a variety of environments his opportunities for learning skills related to social competence increases.

Interestingly, our notion of social competence also has implications for the basic definition of handicapping conditions. Tredgold (1937) stated that the severity of a handicap was the degree to which an individual needed the mediation of another person in order to function in society. Thus, the amount of social assistance received from others defines the severity of handicap. As assistance or supervision is faded, the severity of the condition subsides. This relationship is exemplified in vocational programs where proximity fading gradually decreases the supervisory role of the instructor (Pumpian, Note 4; Wehman et al., 1982). Further, Brinker (Note 2) has stated that "as the number of contexts within which an individual can interact increases and as the complexity of social interactions within contexts increases, the level of an individual's handicap decreases." This point is consistent with our idea of the range of environments. That is, as social competence increases, the individual must correspondingly be viewed as less handicapped.

Social Perception

When handicapped persons become more proficient in a variety of environments there is a correlated effect upon how they are perceived by the nonhandicapped population. For example, in the Technological Employment

Project (Gaylord-Ross, Forte, & Gaylord-Ross, Note 5), seriously handicapped students were required to handle technically complex equipment, e.g., viscosity chambers, wore laboratory garb like safety glasses, and had to ambulate through a laboratory crowded with equipment and technicians. Visitors to the project undoubtedly remarked that the students did not appear "that" handicapped. While a majority of the students did have psychometric diagnoses in the moderate range of mental retardation, the social perception of them in this impressive technological context led observers to believe that they were "not very handicapped." Perske (1972) has referred to the "dignity of risk" as the circumstance where handicapped students accrue dignity when they are placed in settings where there are tangible risks, e.g., school failure, danger crossing streets. The social perception of handicapped persons is elevated when a nonhandicapped observer realizes that she or he could not immediately step into the vocational role and perform a task successfully.

Social Interaction

Training for increased social competence appears to elevate the social perception of handicapped individuals. In turn, the nonhandicapped person is more likely to socially interact with this more competent handicapped peer. Strain (1981) has reported data which indirectly support this notion: working with mildly handicapped and nonhandicapped children of elementary-age, Strain reported improvements on measures of positive social interaction and social attraction when an intervention package was implemented consisting of assigning handicapped children as team captains, manipulation of the handicapped child's score to ensure she or he won prizes, and allowing the handicapped child to distribute the prizes to teammates. Replication of a similar procedure with severely handicapped populations would be most useful. Given the potential for training severely handicapped students to perform technical work skills, vocational contexts may be useful settings for promoting the actual and perceived social competence of handicapped persons.

IMPLICATIONS FOR RESEARCH AND POLICY DEVELOPMENT

Social Integration Policy

A number of specific policy questions are embedded in the issues surrounding social integration of students with severe handicaps. A primary question is simply whether the social integration of students with severe handicaps is feasible within public school systems. While "feasibility" may be considered to be a function of a complex set of variables (Guralnick, 1981b), existing research convincingly demonstrates the *possibility* of integrating even the most severely handicapped students (Russo & Koegel, 1977; Stetson, 1979; Voeltz, 1980, 1982). These demonstrations highlight the importance of environmental factors in determining the outcomes of integration efforts. The critical policy issue thus shifts from "is this student too handicapped?" to "is this environment sufficiently supportive?" to achieve positive integration outcomes.

A second question with important policy implications regards whether social integration experiences produce developmental growth for the handicapped student involved. Certainly, there are theoretical reasons to believe that integration does facilitate social and cognitive development (Apolloni & Cooke, 1975; Bricker, 1978; Brown et al., 1979; Hartup, 1978). However, at present, empirical evidence for developmental effects due to integration is limited at best (Peck & Cooke, 1983; Semmel, Gottlieb, & Robinson, 1979). Again, existing demonstrations of increases in relevant social skills with specific interventions in integrated settings support the *possibility* of significantly accelerating social development (Peck et al., 1978; Strain et al., 1979). However the limitations of these studies must be acknowledged, particularly with respect to the moderate rather than more severely handicapped nature of the populations studied. Finally, the issue of identifying developmental effects due to integration carries all of the conceptual and philosophical complexities of the general issue of the educability of children with severe handicaps (Baer, 1981; Noonan et al., 1982; Kaufman & Krouse, 1981). A satisfactory empirical answer to this question will be most difficult to obtain.

A third set of policy issues center around the effects of social integration on nonhandicapped students. The typical focus of research in this area has been on changes in the attitudes of nonhandicapped students toward handicapped peers. The research reviewed above suggests that positive attitudinal outcomes are most likely when systematic, structured contact is arranged between nonhandicapped and severely handicapped students (Brinker, Note 2; Voeltz, 1980, 1982). Additionally, some evidence suggests that contacts designed to promote leisure/recreational relationships rather than instructional (i.e., peer tutor) relationships may be more likely to promote positive cross-group social interaction (Haring et al., Note 3).

Research Needs

The suggestions for research outlined below reflect an emphasis on the need to expand existing knowledge and procedures for promoting the social integration of children with severe handicaps.

First, the need exists for process-oriented studies with more severely retarded populations than have typically been investigated. These studies should provide descriptive information regarding the nature of social interactions between nonhandicapped and severely retarded children, test the usefulness of procedures demonstrated with preschool-age and moderately retarded populations, and provide feedback regarding the effects of additional child-centered and environment-centered interventions. In this context, the use of multiple dependent measures, tapping behavioral and attitudinal change (e.g., Strain, 1981), will yield a more substantial data base from which researchers can more clearly interpret the effects of integration efforts.

A second major research need is related to issues of the external validity or generalizability of existing and future demonstration studies. Specifically, additional attention must be devoted to assessing possible interactions between characteristics of settings, participants, and treatments if accurate predictions are to be made regarding the replicability of results (Campbell & Stanley, 1963; Kazdin, 1981). The increased use of between-group factorial designs, where treatment effects are contrasted across types of subjects or settings, or where differing values of the treatment variable are contrasted (e.g., Voeltz, 1980, 1982) represents one strategy for the direct assessment of external validity issues (Kazdin, 1981). Intra-subject designs with systematic replications (Sidman, 1960) or multi-element designs, where treatment effects are directly contrasted in varying contexts represent idiographic approaches which generate data related to the external validity of results.

A third area in which further research is immediately needed regards clarification of issues related to the nonhandicapped children involved in social integration efforts. While all integration projects proceed under the assumption that no harm is done to participating nonhandicapped students (Scriven, 1976), few attempts to empirically investigate this issue have been reported. The anecdote reported at the beginning of the present chapter suggests that, indeed, some positive effects may accrue to nonhandicapped children who participate in social integration programs. Research directed toward assessing such effects might include measures of affective growth, moral development, or social cognition.

Additional issues related to nonhandicapped children which merit investigation include identification of child characteristics which predict differential outcomes of social integration efforts. Existing data suggest that both the sex and the age of nonhandicapped peers may be associated with differences in attitudes toward handicapped peers (Brinker, Note 2; Gottlieb, 1978; Gottlieb & Switsky, 1982; Voeltz, 1980). If these or other factors impact peer attitudes, important implications would be derived for both the selection and preparation of nonhandicapped children for integration experiences.

SUMMARY

The social integration of individuals with severe handicaps represents a social-political goal consistent with the philosophical principles of a pluralistic, egalitarian society. A theoretical model is advanced regarding the educational value of social integration. The contribution of research is seen in the development and evaluation of programmatic strategies for achieving social integration goals. Existing research demonstrates the *possibility* of achieving positive behavioral and attitudinal outcomes when integrating severely handicapped and nonhandicapped students, and suggests some specific intervention procedures for promoting these outcomes. However, the existing empirical knowledge base is limited to a rather narrow range of subjects, settings, and interventions, and must be systematically expanded if research results are to be more useful to policy makers and teachers. Suggested directions for future research include increased attention to outcomes for students with more severe levels of mental retardation, more systematic assessment of the generalizability of research findings, and more thorough study of effects on nonhandicapped children.

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CHAPTER 11/
CURRICULA WITHOUT RECIPES: A CHALLENGE TO TEACHERS AND A PROMISE TO SEVERELY MENTALLY RETARDED STUDENTS

RICHARD P. BRINKER

Educational Testing Service

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The two points by which to measure the worth of a form of social life are the extent to which the interest of a group are shared by all its members, and the fullness and freedom with which it interacts with other groups. An undesirable society, in other words, is one which internally and externally sets up barriers to free intercourse and communication of experience. A society which makes provision for participation of all its members on equal terms and which secures flexible readjustment of its institutions is democratic (John Dewey, 1916, p. 99).

CURRICULUM FOR SOCIETY

In the last decade American society has become more democratic by eliminating some of the barriers which have prevented mentally retarded persons from full participation. However, changing a law does not change custom nor does it equip persons with severely limited skills with the means for achieving social participation. The education system clearly has been given the opportunity to make broad changes in the customs of American life as far as participation by handicapped individuals is concerned. To actualize these changes the educational curricula has been broadened to include the most basic skills of human adaptation. Moving around the environment, making contact with people and objects in the environment, taking care of one's own biological needs, communicating with others, gaining access to vocational, recreational, and independent living environments are becoming crucial components of educational curricula. As aspects of education such basic skills are new. However, the scientific knowledge upon which to base the teaching of such skills has expanded dramatically over the past two decades (Osofsky, 1979; Schiefelbusch & Lloyd, 1974). The translation of knowledge about human development into curricula is the essence of the present chapter. The argument will be made that such a translation can only be accomplished by teachers who know their students intimately. Effective curricula for severely retarded students cannot be found by systematically synthesizing all the currently available curricular efforts (Cohen & Gross, 1979). Curricula cannot be constructed by translating laboratory research paradigms into educational procedures (Mittler, 1977). Neither can curricula be constructed by producing exhaustive inventories of environments and by postulating the skills which might be required to function in those environments (Brown, Nietupski, & Hamre-Nietupski, 1976; Vincent et al., 1980). Nor can curricula for the severely handicapped be found nestled in the writings of developmental theorists (Lewis & Taft, 1982; Bricker, 1982; Brinker & Bricker, 1980). Curricula must ultimately be developed within a relationship between teacher and student. The teacher can choose any one of the perspectives referred to above but ultimately she or he must see in the child's behavior seeds of the skills which will lead to increased social participation. Without recognizing the student's existing preferences, behavioral probabilities, and limitations as the seeds for subsequent development, any educational objectives will likely miss their target (Guess & Siegel-Causey, this volume).

This chapter will not defend one preferred curricula over another. Rather a short history of the evolution of the concept of curricula for severely handicapped students and the "flexible readjustments" of educational practices which have occurred will be provided. Three approaches have emerged in this evolution: 1) an operant or applied behavioral approach; 2) a developmental approach; and 3) an ecological approach. After briefly discussing each I will point the way toward a synthesis between behavioral, developmental, and ecological perspectives as the basis for curricula of the future. The synthesis must come to fruition in the teaching activity of teachers who want their students, first and foremost, to be able to go more places, interact with more people and derive fuller pleasure from such interactions.

CURRICULA FOR SEVERELY MENTALLY RETARDED STUDENTS

The concept of curricula for severely retarded students is relatively new. By definition, severely retarded individuals previously were regarded as incapable of learning (Wolfensberger, 1969). Thus, a curriculum of learning goals made no sense for that population. At best individuals could be taken care of and protected from a harsh society and relieved of responsibility for being productive members of society.

The emergence of a behaviorist conception of man as a machine, largely programmed by the environment, introduced the possibility of curricula for even the most severely retarded people.

The Operant Approach

The optimism of operant researchers that behavior of retarded persons could be changed was supported by increasingly strong federal commitment to research and services for retarded individuals. Prior to the Kennedy Administration the primary mode of care for severely retarded individuals was custodial services in residential institutions. Empirical case studies demonstrated that even the most problematic behaviors could be changed. Children who were inflicting severe harm to themselves through stereotypic self-destructive behavior were taught to stop such behavior. Children who used no functional language were taught to use words appropriately. Children who had never been trained to use a toilet, to eat appropriately, or to dress themselves were taught to do so (e.g., Bijou & Baer, 1967; Whitman & Scibak, 1979). Thus ended a phase of total dependency for some individuals which had been a major factor in defining them as severely retarded. If training through operant techniques could produce such reversals in our conceptions of people, then surely these individuals were not inherently different. Rather the concept of retardation became an interactive one which required not a specification of inherent limitations of individuals but rather a statement of capabilities and a statement about the environments which either supported or discouraged those capabilities (Hobbs, 1966; Cantrell & Cantrell, 1976; Filler, Robinson, Smith, Vincent-Smith, Bricker, & Bricker, 1975).

Experimental Analysis The operant or remedial approach (Guess et al., 1978), is based upon the belief that behavior is a function of a history of operant conditioning (Skinner, 1953) and that the influence of such a history could be changed by new contingencies in the present. The control of behavior was to be found through an experimental analysis of events antecedent and consequent to the behavior. If manipulations of antecedent and consequent events do change the rate of behavior, then the antecedents can be defined functionally as discriminative stimuli and the consequences can be described functionally as reinforcements. The key elements of the operant system require an experiment to make the translation from the descriptive language "antecedents" and "consequences" to the functional language of "discriminative stimuli" and "reinforcements." Thus, the essence of this perspective is that the teacher obtain data about the rate of behavior when there are specific antecedents and consequences for that behavior, as well as data about the rate of behavior when such antecedents and consequences are not available. A comparison of these two types of rate data provides the basis for understanding that the behavior of interest is controlled by discriminative stimuli and reinforcements.

Cues, Prompts, Feedback In reality, this experimental framework is somewhat tangential to the everyday practice of applied behavioral analysis in the education of severely retarded students (Bijou, 1980). The behavioral approach as practiced relies heavily upon techniques of behavioral shaping of successive approximations to a target behavior, modeling, physical prompting, and fading of prompts. In addition there has emerged a very different form of the English language (Special Education version) intended to be comprehensible to retarded students. Statements such as "Nice tracking" to "reinforce" a severely handicapped one-year-old for looking continuously at a moving object, or "What doing" to inquire about a child's activity, or "Show me standing" to determine if a child understands action to which the verb "stand" refers have become part of the technology which makes educators "special." Apart from the comical aspect of a world full of nice walkers, nice lookers, nice talkers, nice touchers, and nice sitters such special education folklore is usually justified by ad hoc explanations that such techniques provide information feedback or are necessary for children at the "telegraphic stage" of language. Similarly, physical prompting of a response, that is, overriding the child's response system with your own muscles, often becomes the starting point for teaching any skill (Popovich, 1977).

Task Analysis of Skills The behavior which can be most readily defined for an experimental analysis, is usually a response in the person's repertoire. Thus, aberrant behaviors make excellent targets for an experimental analysis because people can readily see that a child has just hit his head against a wall, or vomited. Since such behaviors are so readily identifiable it is not difficult to address the question of what occurred just before or after them. However, it is more difficult to define the target behavior which is *missing from* a person's repertoire. Yet a successful curriculum depends upon identifying such target behavior and a series of objectives which bridge the gap between what the child can do and what is desirable for him to do.

Task analysis is the process of reducing a particular behavior into smaller component behaviors. The nature of the components varies depending upon the perspective of the educator with regard to the behavioral goal. White (1980) noted that the most common perspective from which tasks have been analyzed has been the idealized behavioral model, that is, analysis of the topography of the behavior as exhibited by a person who has mastered it.

Mastery of a behavior has many possible definitions. One can focus directly upon the movement pattern and require a specific form of movement involving specific musculature. For example, Moss and Hogg (1981) developed categories for classifying manual grips into nine categories based upon the relationship of the fingers to the palm and thumb when picking up objects. An educational objective which specifies the topography of behavior is "Picks up object using thumb in opposition to the first and second fingers." Instead of concentrating on response topography, one could define mastery in terms of the speed with which a behavior is executed after a cue. For example, "Bill will select a cup within 5 seconds of the command 'Give me the cup'." Some have defined behavioral mastery in terms of behavioral rates or proportions of occurrences relative to opportunities. For example, "Mike will raise his head 45 degrees 75 percent of the time he is instructed, 'Lift your head Mike'." Objectives can also be defined in terms of functionality without attention to specific response topography, reaction time, or rate. For example, "Claudia will request a preferred object from another child."

The way in which one defines mastery of an objective will influence the way in which the task is analyzed. A task analysis of clapping hands in imitation would look different depending upon the teacher's educational purpose for selecting that task. If the teacher is interested in establishing compliance to a direction then the amount of time it takes the student to respond after the direction would probably be included in the task analysis (e.g., responds after 15 seconds). On the other hand the teacher may have selected "clapping hands in imitation" because imitation provides a framework for establishing a turn taking dialogue. In that case the teacher might choose to reinforce any behavior which the child emits after the model so that the child first learns the turn taking character of imitation games before learning to match the form of behavior to the model's behavior.

Clearly, there are no "right" task analyses. Usually the behavioral topography, the sequence of interaction between teacher and child, the structure of the materials or qualitative criteria involving rate or percentage correct provide the basis for task analyses. Unfortunately the criterion for selecting one type of task analysis versus another is often unclear—especially to the child. Consider an example in which I was trying to teach a 19 month old Down syndrome boy to imitate simple actions.

> The course of learning had not been smooth but after three weeks, four sessions per week, Nigel had imitated ringing a bell three times in succession and had imitated stacking one block upon another three times in succession. The next action to be imitated was to raise his hands over his head. On the first trial Nigel raised his hands triumphantly but looked surprised when I gave the reinforcement which had been functional in earlier learning sessions. The second trial, he tentatively raised his hands over his head after my saying "Do this." and demonstrating the action. "Way to go, Nigel," I said as I popped a chocolate piece in his mouth muttering to myself, "Just one more time, Nigel." His lower lip begins to tremble and his eyes begin to fill with tears. On the third demonstration, Nigel breaks down crying after I say "Do this." and the session comes to an unhappy end. Later in the day, Nigel solved the mystery of how chocolate, praise and all the good things for which he'd previously worked upset him. As his mother entered the classroom at the end of the day, Nigel, sitting on the floor, grinned at her and raised his arms over head. She extended her arms and said, "Sure I'll pick you up" which she did and they happily left.

Nigel was being taught what we thought to be precursors to symbolic representation—imitation of gestures. However one of those gestures already *functioned* symbolically. Reaching his hands above his head communicated "Pick me up" to his mother. We missed our target.

Critique of the Operant Approach While the early successes of applied behavioral analysis were encouraging and opened an era of hope for the severely retarded, many of the early successes involved either increasing or decreasing the frequency of behaviors which were already in a student's repertoire (Bricker, 1970). When people began working with younger severely retarded students who had never been in residential institutions, it became clear that the educational problem was not primarily elimination of aberrant behaviors (Bricker & Bricker, 1976). Rather, younger students simply had limited response repertoires. When the behavior is not in the student's repertoire, but has to be shaped through the use of physical prompting, reinforcement of successive approximations, and fading of cues, the scientific foundations of the process become less clear.

The basis of an operant analysis is that the behavior to be studied is freely emitted. Many of the curricula for use with severely retarded students are not based upon an analysis of freely emitted behavior. If one examines carefully Skinner's early papers (1931, 1935b) one finds several key distinctions which have not been translated into applied behavioral analysis. These are his definition of operant behavior and the way he experimentally analyzed operant behavior. He argued that the stimulus(S)–Response(R) reflex arc accounted for a limited range of behavior. A broader range of behavior could be found outside the search for reflexes and the stimuli which automatically elicit them. Operants were initially described as behaviors for which no eliciting stimulus could be found. Basically, Skinner argued (1935a, 1938), operant behavior is best defined by its function rather than by its form. Thus, the operant of bar pressing for the rat was the same generic class (i.e., functionally the same behavior) whether the actual form of the behavior involved pushing the bar with the nose, the front feet, the back feet, the tail or whatever. The important point in this definition of behavior in generic terms is that it allows psychologists to look at a more macroscopic level of analysis by equating different muscle movements as members of the same response class. The response classes are defined in terms of a functional relationship between the behavior and environmental circumstances. To study such behavior it is necessary to arrange an environment so that *whenever* a response is emitted, under certain conditions, that response is reinforced on a predetermined schedule. The organism is free to emit as many or as few responses as it wants and the rule still applies. Thus, in operant conditioning, the student really controls the environment for as long as she or he is in that environment. Often the environments in which severely retarded students are taught differ considerably from an operant conditioning environment. Typically the contingencies in a special education environment operate only as long as the teacher is working on a particular lesson. This can lead to confusion. For example, saying things in response to a language lesson may be reinforced during that lesson but go unnoticed during fine motor skills training. Contingencies for freely emitted behavior must be incorporated into curricula for the severely retarded if truly generalized learning is to result.

The Developmental Model

The developmental model is based upon a large body of data demonstrating that children master skills at different ages, and some skills are consistently mastered by children before other skills (Cohen & Gross, 1979). Application of this model to mental retardation implies that the rate of development is slower than normal but the pattern of development and the stages of development are essentially the same for retarded and normal individuals. The task for the developmental interventionist is to identify the current developmental level at which a child is functioning and to select educational objectives which are just above that level. Developmental progress is produced by selecting objectives which are an "optimal mismatch" (Hunt, 1961) between new task requirements and existing skills.

Theoretical Developmental Models Unfortunately in attempting to translate developmental psychology into applications for students, educators focused more upon the content than the process of development (Papert, 1980). Most notably excluded from curricula emerging from a developmental perspective are two principal thrusts of developmental research: 1) the concept of generative rules; and 2) concern with the structure of behavior within various domains (Fischer, 1980; Hupp & Mervis, 1981; Bransford & McCarrell, 1974).

A generative rule is a rule used to produce a variety of new responses to situations. For example, a pluralization rule in English would be "Take the singular form of the noun and add -s to the end." Clear use of generative rules occur when children refer to two mice as "mouses" or make statements like "we walk on our foots." Although these children probably never heard their parents make such statements, their "mistakes" are logical extensions of generative rules.

The structural approach refers to a theoretical framework within which behaviors from different domains or situations are interpreted in terms of the same underlying general principles (Piaget, 1970). For example, Bates (1976) noted the structural similarity between communicative vocalizations and means-ends behavior. Examples of means-ends tasks are using a stick to retrieve an object out of reach or pulling on the tablecloth which supports an object in order to bring the object within reach. The means-ends problem is designed to assess whether a child can distance himself enough from his desire for a particular object (end) and focus on some other object as a means to obtain the desired object. Bates (1976) argued that early vocalizations functioned as means of obtaining objects in the environment and also as a means of engaging parents in conversational play. For example, a child might look at and point to an object in front of him and say "aba." The object becomes a topic around which an interaction is focused. Alternatively, the child might really want an object to play with so she obtains it by pointing at it and whining "bobo" which the parent interprets to mean "I want that object." By equating various vocal interactions and methods of interacting with objects as part of the same "means-end" structure, the structuralist has defined a larger *whole* from which a large variety of *elements* can be derived. The structuralist logic, thus, proceeds in the opposite direction from one which argues that a structure can be built by teaching a variety of elemental behaviors. Instead structuralists identify broad commonalities in the pattern of behaviors applied to people and things and thereby construct the child's way of interacting with the world. Once the child's world view has been described one can see ongoing behavior as examples of the rules in that world. The important feature of understanding behavior in structural terms is that one can individualize teaching by changing the situation to challenge each child's unique expression of the structural rule. Such challenges are the basis for the "optimal mismatch" between environmental demands and existing capabilities which Hunt (1961) argues is the impetus for subsequent development.

Normative Developmental Approach In practice, developmental models often utilize developmental checklists of behaviors in various domains of functioning. For example, Hanson (1977) provides a developmental curriculum for Down syndrome infants which includes many items from the Bayley Scales of Infant Development (Bayley, 1969). Other popular developmental curricula include information from research and normative developmental tests for young children which provide a basis for arranging behaviors in sequence based upon the chronological ages at which such behaviors are normally acquired (Brigance, 1978; Cohen & Gross, 1979; Shearer, Billingsley, Frohman, Hillard, Johnson, & Shearer, 1972). For example Brigance (1978) presents picture vocabulary items in the speech and language skills domain which are scaled in terms of age. Using this framework the child who knew few words would be taught *dog* before *man*, and *airplane* before *cup*. The child being taught the Portage curriculum would be taught to say "all gone" (item 13 in language domain) before being taught to answer the question "What's this?" with an object name (item 20). The rationale for the order in selecting the objectives is that on average children of various ages perform differently on such items. However, there is no logical reason that some of these items should be mastered before others. More importantly, the relevance of these sequences of behavior derived from normative scales to the sequence of development for severely retarded children is open to considerable question (Hogg, 1975; Lewis & Wehren, 1982; Garwood, 1982; Riechle, Williams, Vogelsburg, & Williams, 1980; Switzky, Rotatori, Miller, & Freagon, 1979).

Critique of the Developmental Model Normative developmental curricula disregard both the structure of the task and the cognitive structure which the child brings to the task. We may be asked to teach the child at 20 months to select the appropriate object when asked "Give me the car." versus "Give me the cup." Then, sixteen months later, at 36 months of age, a receptive vocabulary item may be taught asking for the "ball" versus the "doll." These checklists do not provide the structural rule for generating either of these items. Thus, the meaning of the educational objectives is lost. The curriculum can be implemented whether or not the teacher knows that the *car* versus *cup* item was one way (among a large variety of others) to determine whether the child can symbolically represent an object with the correct word. The *ball* versus *doll* item does not address primarily the question of symbolic representation, but rather asks whether the child can discriminate sounds within words at the phonemic level since the primary difference between the two words *ball* and *doll* is the *b* and *d* phonemes. If items were phrased in more conceptual terms, it would be much easier for teachers to develop individualized curricula which were more developmentally appropriate. Such curricula would include specific behavioral criteria which were conceptually and theoretically related both to the structure of the individual child's skills and to the structure of both the previous and the subsequent curricular objectives.

Thus, the "developmental model" which has recently been challenged (Hogg, 1975; Switzky et al., 1979; Vincent et al., 1980) deserves the attack. However, the attack more rightfully should be phrased not as an attack on a *developmental* basis for curriculum but rather as an attack on a *normative* basis for curriculum. The normative curriculum objectives are dissociated from the behavior in which the child is usually engaged, they are dissociated from the environment in which the child usually behaves or will be required to behave in the future, and finally they are often dissociated from each other. An understanding of development offers not this list of dissociated objectives but a heuristic (tool) for making the skills which we teach the child intrinsic extensions of what that child can already do (Papert, 1980).

The developmental model of a special education curriculum should not provide a series of educational objectives. Rather, the developmental model should, when applied correctly, generate a hierarchy of questions with which we can discover the competencies of handicapped learners and transform the situations in which those competencies are expressed so that the child's skills become more complex (Brinker & Lewis, 1982). This discovery process does not require a dissociated list of behavioral objectives and their associated chronological age. Rather it requires intimacy—the construction by teachers of a view of the student's world which, if not shared by the student, at least incorporates full understanding of differences.

Conflict Between Operant and Developmental Models

Unfortunately, the competing conceptions of human beings becomes the dominant theme whenever the developmental and operant schools are compared (Langer, 1969; Baldwin, 1967). The portrayal of the operant view is that humans are passive and almost wholly malleable by the forces of the environment. Langer (1969) characterized humans from the behaviorist view as mechanical mirrors. The portrayal of the developmental view is that humans are active and creative, more in control of, than controlled by environmental forces. However, the major force which changes humans is biological maturation. In clockwork fashion development unfolds, post hoc explanations are offered but the mechanisms are uncontrollable. The developmental study of behavior appeared to the operant group to be like astronomy, the pattern could be described but not manipulated. Clearly there are grounds for a debate between developmental and operant perspectives. However, the heat of the debate is confusing to both parties and only a few individuals have argued that some cross fertilization of ideas from experimental and descriptive studies of development is in fact possible (Hunt, 1961; Bricker, 1970; Brinker & Jaynes, 1983; Catania, 1973). The general consensus, however, has been that the developmental perspective has little to offer the operant psychologists trying to solve pressing problems (Baer, 1973) while the operant perspective has nothing to offer developmental theory (Piaget & Inhelder, 1969).

Much of the fervor of the controversy really involves each side trying to mold the other into something they are not. The developmental researchers acted as though they carried the torch of true science and they need not sully their science by applying it to severely handicapped students. On the other hand the operant researchers did not welcome the information available from developmental psychologists (Baer, 1973). The belief was that the developmental position offered a program only for describing behavior and waiting for time to produce changes. Obviously, the problems of severely retarded people call for some action and simply waiting for improvement is not an acceptable course. However the operant program of research seems at times to be intentionally opposed to the notion of developmental sequences even when educators attempt to translate such information into active intervention plans (Bricker & Bricker, 1974; Guess, Sailor, & Baer, 1974).

There are positive signs that the field has now moved beyond the entrenchment within either a developmental or a strict operant perspective (Brinker & Bricker, 1980; Guess et al., 1978). More importantly, the demonstration that severely handicapped students can learn created new possibilities for retarded people to go places they had not been allowed previously, to do things they had never had the opportunity to do, and to form meaningful relationships with people they never could have met in institutional environments.

The Ecological Model

Lou Brown and his colleagues at the University of Wisconsin and Lee Gruenewald and Jack Schroeder of the Madison Public Schools have articulated most clearly the use of an ecological model of intervention for severely handicapped students (Brown et al., 1980). The ecological model has several important features:

1. A fundamental commitment to participation by severely handicapped students in the life and environments within the community.
2. An analysis of major environments within a community based upon an inventory of public places and their physical design.
3. An analysis of activities which generally occur within the various environments in the community.
4. Task analysis of the skills necessary to participate independently in selected activities in environments and a specification of the supports necessary for facilitating at least partial participation in the widest functional range of activities.

The goal of the ecological model is to move severely handicapped individuals towards ultimate functioning. Ultimate functioning is described by Brown et al. (1976) in terms of the degree to which severely retarded persons are able to function productively in the widest variety of community settings which are appropriate to that person's chronological age.

Analyses of environments and specification of skills within these environments have been developed by Sharon Freagon and her colleagues (1981) as well as by the Madison group. For example, an ecological inventory of a grocery store provides a listing of the equipment (e.g., grocery carts, scales), the departments, and the specific layout of products in each aisle of the store. From the environmental analysis a variety of reading, math, language, conceptual judgement, and sensorimotor skills are derived (e.g., counting items, locating aisles by numbers, answering questions, choosing a check out line). Task analyses of different activities (e.g., using aisles appropriately, selecting grocery items, paying for groceries) are then delineated as the basis of the curriculum in the community context.

A critical feature of the ecologial perspective is the belief that the structure and stimuli within the environment provide the basis for what will be learned and also the supports to maintain the behavior. Thus, severely retarded students do not have to learn prerequisite skills to gain entry into community environments. Rather, the ecology itself is a major part of what must be learned. Since functioning is supposed to occur within the community ecology as an actual goal, there are valid empirical reasons for teaching in that ecology rather than teaching within a classroom and "hoping for generalization" to the community setting (Stokes & Baer, 1977).

The ecological approach incorporates the second type of objectives discussed by White (1980), objectives which emphasize the critical functions of behavior rather than the topography of behavior. White (1980) favors the critical function approach over the behavioral model approach because "The 'do exactly as they do' approach to goal setting overlooks the possibility that there may be more than one way to accomplish the same basic end" (p. 49). Brown et al.'s (1980) notion of critical functions established through partial participation in a community setting, provides further illustration of an important aspect of the ecological perspective. For example, independent living is facilitated if an individual knows how to count money in order to shop, use public transportation, and generally to participate in our consumer oriented society. However, the discrimination skills required to distinguish all of the bills and coins, the memory skills to associate each bill and coin with a value, and the mathematical skill to add and subtract values correctly may never be attained by severely retarded individuals. Rather, than concluding that severely retarded individuals therefore cannot live independently because they cannot handle money, some modification of behavioral criteria is required so that such individuals can at least *partially participate* in consumer activity. For example, by using only dollar bills and counting these out to match the purchase price, the severely handicapped person can rely on the salesperson's mathematical abilities to make the right change and request additional dollars if necessary. Obviously, the severely retarded person could be cheated by an unscrupulous salesperson but the risk of such victimization is more than offset by the potential for living at least a partially independent life. Moreover, serious "robbery" can be prevented by having the assistance of a more competent person to plan what will be purchased and to estimate its cost.

Critique of the Ecological Model The ecological model holds the most promise as a framework for curriculum development. Very few previous efforts to change behavior have focused broadly on the environment and its structure (Beveridge & Brinker, 1980; Bronfenbrenner, 1979; Cantrell & Cantrell, 1980; Willems, 1977). Therefore, it is a positive step to define the environments in which people live and to analyze components of these environments which can be used both to teach severely retarded persons functional skills and to maintain those skills.

Nevertheless, environments can be as varied as the people living in them and the ecological model does not provide any clear principles by which to select environments within which retarded individuals can participate or to evaluate environments of different communities. Given the absence of environmental selection and evaluation principles there is a risk that the ecological model will result in the inappropriate adoption of lists of objectives from one community which may not be appropriate to other communities. For example, one can list the potential learning contexts and skills to be acquired in a grocery store (Freagon et al., 1981). However, a severely retarded person living in Manhattan may not need to know how to shop in the grocery store to reach a criterion of ultimate functioning since some grocery stores in Manhattan will deliver directly to one's apartment. Thus, the severely retarded person in Manhattan may need a completely different set of "shopping skills" than the person in Pisgah, Ohio even though shopping ecologies exist in both places.

At present the only method for selecting environments in which severely retarded persons can be taught to participate is common sense. This is not a bad method but it does have certain inadequacies when one applies it to selections in communities other than one's own. Some communities have more and different stresses in comparison to others. Thus, the ecological model will logically result in very different curricula in different places. That is a positive feature of it. However, the danger arises when one borrows the ecological curriculum from some other community and applies it elsewhere. Each child's ecology differs and those differences should become an inherent part of each child's individualized program.

These cautions are not directed as criticisms of what has been accomplished through an ecological perspective. Rather they should alert one to developing any notion that there exists a unitary *ultimate functioning* (Brown et al., 1976) or a particular specific "next environment" (Vincent et al., 1980). Both are constructions of the evolution of our effectiveness in enhancing the development of severely handicapped students.

THE AIMS OF SPECIAL EDUCATION

Curriculum goals can be derived from each of the perspectives described. The goals from the various perspectives, however, may be quite different in content and these differences have fueled the fires of controversy favoring one approach over another. For example, the operant approach was, historically, the first model for embarking upon a course of change in the lives of severely handicapped individuals. It came under attack by developmentally oriented interventionists because it did not capitalize upon the structure of behavior as it emerges developmentally. When the curriculum goals are something other than the deceleration of aberrant behavior or the acceleration of the rate of adaptive behavior already in the repertoire, then some criteria are needed to determine what to teach and in what sequence. The selection of behavior to modify or teach has always been a problem from a behavior modification perspective. The developmental literature is a more objective source of goals than simply one's own intuition about what to teach next. Unfortunately, if development is viewed as a forced march from "stirring in a cup with a spoon" through "sorts 15 transistors into 3 groups within 3 minutes," severely retarded students have an inordinately long infancy. Year after year the same educational objectives involving the same preschool materials are attempted with precious little change in behavior. Clearly, the basic skills which severely handicapped students lack are not being taught by changing objectives from "puts three pegs in a line" last year to "puts five pegs in a line" this year.

The evolution of these three curriculum approaches has matched the evolution of service delivery systems. When the dramatic behavioral changes were being made through operant techniques most severely retarded persons were being served in residential institutions. As school systems began extending services to severely retarded children at increasingly earlier ages, the elimination of many behaviors which were typical within institutional settings was no longer the major problem. Rather the development of new skills from limited repertoires has become the major problem. As severely retarded students become more visible within schools they become more visible within communities. With visibility comes the possibility of fuller participation in community life.

Where is curriculum likely to evolve in the future? For the majority of severely handicapped students the educational problem is how to build new, more complex behaviors on the foundation of a few simple behaviors. Each of the curriculum models can be implemented exclusively through careful specification of the topography of specific response forms in a fixed linear instructional sequence. From the operant perspective the new vocabulary word can be described and the contingency rules and methods of using and fading prompts can be stated without ever linking this new word to the messages which the student may already convey without words. From the developmental perspective, one can generate a list of objectives which fragment the natural rhythm of activities into separate lessons: the head lifting lesson, the rolling over from side to back lesson, the reaching lesson, the making sounds lesson. From the ecological perspective, there is not a clear basis for determining which skills should be taught, in which environments children should partially participate, in which environments fuller participation should be sought, or how to build upon existing ecologies to transform the life space of the child. Preparation for functioning in the "next context" can be selected as a goal even though the "next context" may not be particularly educational for any children. Each of these models would benefit from a consideration of Dewey's comments about the aims of education.

Dewey (1916) suggested that there are three qualities to good educational aims:

1. An educational aim must be founded upon and an outgrowth of the existing activity of the child.
2. An educational aim must be flexible so that it can be translated into a method for cooperating with the activities of the learner in a variety of contexts.
3. An educational aim must be general enough so that even though a specific target is mastered, the aim is to continue the activity successfully in new contexts.

Changing the behavior of severely retarded students should begin by first understanding the contingencies which control the existing repertoire of behavior. Although we may know the behavior which we want to teach, we should perhaps not approach such teaching with the tunnel vision characteristic of past efforts. Specifically, the behaviors which are objectives should be shaped in teaching moments offered to us by the ongoing behavior emitted by our students. Such efforts to achieve "incidental" or unobtrusive learning are not only beginning to appear in research involving the severely handicapped, such procedures are being found superior to the traditional discrete trials teaching procedures (Cavallaro & Bambara, 1982; Mulligan et al., 1982; Wulz et al., 1982).

Ferster (1967) provided a clear statement of the importance of building upon the emitted behavior of children instead of bombarding them with an unrelated series of lessons with the mandatory number of trials. In his paper "Arbitrary and Natural Reinforcement" Ferster presents a teacher's answer to this question, "Why do you walk behind children instead of leading them through the school?"

> 'He feels your protection when you walk behind. If you give him a chance to go any direction, he may be wrong when he goes this way or that. Just follow him. If its a dead end pick him up gently and bring him to the main route. But never think that you know the answer because you are dealing with an individual who may want to go very different routes which for him may be better. That's why I feel more comfortable behind the children so I can see where they're going. . . . Walking behind the child denotes a broad statement of the principle of operant reinforcement. The repertoire may be partially ineffective, however, and these parts will decrease by extinction as the therapist supports, prompts, and otherwise encourages those behaviors which are successful. By beginning with the initial behavior and reinforcers that the child brings to the therapeutic environment we preserve the unique contribution of his own repertoire, and we avoid decisions about his life which are too arbitrary (Ferster, 1967, p. 346).

Finally, the future of curricula for severely handicapped students should capitalize upon the constructivist theory of Piaget. From this standpoint the repertoire of the child viewed within specific environmental demands is the basis upon which the child develops. Piaget assumed that there was systematic order in a child's simplest behaviors. By beginning with this assumption, he was able to detect not only the organization of the world by the child at a given time, but also the reorganization of that world at later times. His most remarkable use of this interactionist framework was in discovering the process by which even the simplest of behaviors such as the sucking and grasping of objects by infants developed into more complex, more functional forms (Piaget, 1952). The discovery of order within the simplest of repertoires was built upon careful observation of those repertoires and their systematic functioning. We have not yet discovered the competent handicapped person because (1) often such people have been in environments which were themselves atypical and (2) we have often been blinded by our objectives, focusing only on the behaviors which handicapped children do not emit rather than carefully describing those which they do emit (Brinker & Lewis, 1982). The interactionist perspective provides an orientation which transforms most of what people do into interesting phenomena the principles of which must be systematically discovered and used to construct the next developmental step.

The alternative is to develop educational tricks supported by speculation from research studies. We hypothesize that we can generate new behavior if we simply teach the student to imitate our own behavior. Yet we find that our generalized imitative behavior is not as generalized as we hoped, after 6 months of training it still takes 1200 trials to teach the first sound imitation (Garcia, Baer, & Firestone, 1971). If we select our goals from developmental theory, from developmental checklists, or from a task analysis of the operation of the vending machine which is in the cafeteria this year, without relating these goals intrinsically to what the student already does, we are doomed to failure. The problem goes beyond special education to the structure of American education in general. The typical educational method offers curricula which are dissociated from students' lives and interests (Papert, 1980). Unless we begin to use curricula which make contact with these lives and interests our educational accomplishments are likely to continue to be mediocre.

Curricula Without Recipes

What is the new educational recipe for teachers of the severely retarded? What can teachers do to develop curricula based on this overview? No recipes which are guaranteed to build that next functional skill on the basis of the existing repertoire can be offered. In a very real sense, teachers must form their curricula based upon the competencies of the unique group of children whom they are teaching each year.

In the age of accountability it does pose a dilemma to try to capitalize on "the teaching moment." There has to be some structure and plan for creating and responding to such moments. How can we let severely handicapped students lead us? It takes a great deal of self confidence to say, "I know this student very well and based upon that knowledge I believe these situations, which I've devised, will challenge her way of doing things and lead her to a new and better way." Nevertheless, we will have to develop the kinds of supportive relationships within schools so teachers of severely retarded students feel confident making such statements.

Curricula without recipes will evolve within a structured approach carefully articulated by teachers to ensure flexibility in meeting individual student's needs. Such an approach will have to incorporate the following to be successful:

1. Commitment to participation by severely retarded students into an expanding world which includes an increasing number of social relationships and an increasing number of environments. Curriculum topics will, therefore, relate to development of functional skills within real life environments.

2. Systematic observation of the responses of severely retarded students to the growing array of environments in which they participate.
3. Analysis of the social and physical features of environments which are consistently associated with various types and probabilities of behavior for individual students. Thus, skills to be learned are derived from analyzing the abilities of each student within the broad framework of functional participation in community life. While recognizing the natural hierarchy of skills within this framework, the individual expression of these skills should be encouraged. Rather than expecting all students to exhibit skills in the same way, teachers should use their knowledge of individuals to allow for differing responses.
4. Curriculum should be envisioned as a generative process, not a set of fixed activities. Curriculum evolves out of the interaction between students and teachers. In drawing upon the wisdom of Dewey and Piaget, curriculum begins with the student's own activity and evolves as the teacher, using her or his knowledge of the student's particular repertoire of skills and information, extends that repertoire. Thus, the student may learn to generalize existing skills to new situations or acquire new skills within this interactive process. The teacher's role is clearly that of a facilitator—arranging the environment to provide opportunities for learning and capitalizing on the student's own activity within the environment to broaden skills.

In summary, curriculum without recipes is seen as a process of preparing students for life. The topics of the curriculum relate directly to the development of skills that allow for participation in the community. The selection of activities is an interactive one. The teacher prepares or selects environments that encourage the development of functional skills. The teacher then builds on the student's own activities within these environments and the student's own repertoire of knowledge and skills to foster individual expression and extension of skills.

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CHAPTER 12/
BEHAVIORAL CONTROL AND EDUCATION OF SEVERELY HANDICAPPED STUDENTS: WHO'S DOING WHAT TO WHOM? AND WHY?

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The right to choose
Options for teaching choice
The choice to be spontaneous
Are we training technicians or teachers?
    Selection of educational goals
    Teaching to the data sheet
Principles for teacher training
Reference note
References

> In setting down narrow and specific objectives and in shaping children toward them by rewarding the responses we favor, we may be force feeding too much. The challenge of these strategies is to assure that the pupil is not treated as a mindless object to be molded as educators see fit. There may be things a child does not want to learn or need to learn and others that he does. . . . (Dunn, 1973, pg. 54).

Over the past 15 years significant advances have occurred in the education and treatment of individuals with severely handicapping conditions. These advances are, in part, a result of a behavioral technology that ushered in an optimism for individuals who in the past were not provided with the learning opportunities to reach their fullest potential in life. The technological accomplishments of applied behavioral analysis have been tauted by many persons as *the* answer to the education and treatment of persons with severely handicapping conditions. Successes in improving the skill levels of these individuals through the use of behaviorally-based procedures were perceived as empirical evidence for the technology; failures were seen as indications that the science needed further development and research. The point might be made that behaviorism arrived on the scene at the right time, and that given a long history of educational neglect, almost anything positive would have improved the life-style of those persons identified as severely handicapped. Nevertheless, the behavioral approach, and the technology evolving from it, has impacted heavily on the education and treatment of this population.

Controversies, both moral and ethical, have been a persistent shadow of behaviorism, and space does not allow the opportunity to fully develop the myriad of issues involved. It is, however, the purpose of this chapter to discuss accomplishments achieved in relation to the issue of control as it impacts on spontaneous and self directed behavior. This discussion is aided by the opportunity to reflect upon a substantial period of time in which behavioral technology has been used extensively with children and adults with severely handicapping conditions.

Our premise may, at the onset, seem like a contradiction. If the technology of behaviorism has produced the techniques and procedures to improve the repertoire of persons with severely handicapping conditions, how might it not always be serving their best interests? This is the very question that we would like to explore in this chapter, being mindful of an earlier observation of Häring (1975) who stated, "Humanities growth in wisdom has not equalled its growth in scientific research" (p. 44).

We begin with a brief review of the technological approaches to the education of severely handicapped persons, and some of the assumptions that are derived, explicitly or implicitly, from them. One needs only to look at the books and journal articles over the past two decades to recognize that current instructional technology for working with severely handicapped persons is heavily oriented towards employing a behavior technology. This orientation is founded in the principles of environmental determinism based on the research and writings of Skinner (1938, 1972) and the academicians and practitioners that have followed him.

At the applied level, behaviorism first found its way into clinical practice with primarily adult psychiatric patients (Ullman & Krasner, 1965), emotionally disturbed children (Lovaas, Schaeffer, & Simmons, 1965) and moderately retarded children (Bijou, 1965). The inevitable extension of behaviorism to treatment and education of severely handicapped persons is now an established fact; one might argue that severely handicapped persons served initially as a convenient population to further develop and assess behavioral principles under the most demanding "battle conditions." Thus, behavioral technology promoted the overall development of the severely handicapped, and the severely handicapped population advanced the development and validity of behavioral technology.

But how has the behavioral technology affected our view of severely handicapped learners in educational, vocational training, and community settings? Does the prevalent behaviorally-based technology used with severely handicapped persons adversely affect the emergence of those human qualities that we are striving so hard to develop in them? Further, does the extensive use of behavioral technology produce some undesirable side effects among those *teachers* who use it?

Explicit in behaviorism is the underlying principle that our actions are determined by antecedent events and the consequences that follow, either positive (and reinforcing) or punishing. This environmental determinism, when applied to the education and training of severely handicapped persons, assumes that others (e.g., teachers, parents, psychologists) have to decide what is in the best interest of the recipients. Thus, we have the potential controller (i.e., well-meaning adults) and the controlled, severely handicapped children and adults. As stated by Landon (1970), "Behavior control is the ability to get someone to do one's bidding. Behavior control technology is the ability to get those effects with precision—which means with the variety, intensity, and duration, and within the exact domain of the controller's interest" (p. 189).

To assist in this controlling process, we have developed an elaborate set of procedures to help determine exactly what we want severely handicapped persons to learn, how they will be taught, where the instruction shall take place, and presumably, why we want them to learn these things in the first place. Our process involves administering assessment scales and instruments, conducting environmental inventories, and compiling this information into specific long- and short-term objectives and goals that are formally sanctioned in IEP meetings. We then task-analyze each skill, select a training procedure, arrange contingencies, modify schedules of reinforcement, prompt, fade, and score. All this is done in the name of technology and in behalf of severely handicapped individuals whom are assumed to be the happy and eventually better-off recipients of such efforts.

We do all of this with the belief that we know what is best for them, based upon how we perceive their roles in *our* society, or that portion of society to which they can comfortably adapt. But what does all this mean about how we view severely handicapped persons, how we view ourselves in relation to them, and how our perceptions translate into both instructional goals and the means used to achieve these goals?

It says first that, as individuals, severely handicapped persons are not capable of deciding what is best for themselves, either as a reflection of how they might better adapt to the social and work demands of our society, or as an expression of their own likes and dislikes. We, in effect, decide for them what will be learned (how, and why), whether they like it or not. Kohlberg and Mayer (1972) observed that in behaviorism the psychologist (or others) assumes the role of a king in deciding what values are to be transmitted to members of a particular society. For the severely handicapped person we have gone even a step further by deciding for them those skills necessary for adapting to our society—skills that reflect to a large part our own values and our own interpretations of conditions necessary for acceptance into our communities. When significant improvement does not occur, we perceive it as a failure of the technology, while failing to recognize that severely handicapped persons might view their place in the world or choose their role in society differently than that which has been imposed upon them.

Closely related to the tendency to specify in detail what a severely handicapped person will learn is the use of procedures that often delimit individual spontaneity. In the zeal to teach (and reach) the educational objectives that are deemed important for the severely handicapped learner, our use of the technology often discourages spontaneous behavior that is not "on task." We tightly control the instructional environment to minimize behavior that is not directly related to the student's IEP objectives, or the procedures used to meet these objectives. Our teachers are judged by the accuracy with which they prompt, fade, reinforce, and so on—and to a great extent, on how well, and fast, they can move the student through instructional programs. Attempts by students to deviate from the program are viewed as interfering behavior, resulting in them being labeled as nonattentive, distractible, or hyperactive. We then apologize for these labels by using more empirical explanations such as, "the reinforcers were weak," "the schedule was thinned out too fast," or "the task needs to be divided into smaller steps." We overlook the fact that maybe the off-task behaviors exhibited by the students may themselves be important to their overall development (if only they had the opportunity to display them). Even more disconcerting, students may not really choose to learn the skill that we have decided is in their own best interest. To use a concept that is troublesome to behaviorism, the students may be trying to exert freedom of choice, and the judgement to use it in a constructive manner.

We are reminded here of a discussion with one of our teachers who was perplexed that a severely/multiply handicapped girl in the class would immediately stop responding whenever she had the slightest suspicion that a contingency was arranged—even for those items and events that were reportedly quite salient for her. (Discussion with other teachers has shown this not to be such a rare occurrence.) Evidently some severely handicapped students are not willing to let us reinforce their behavior; a phenomenon similar to the teenage son of one of the authors who tore up his summer self-improvement contract because he "wanted to be his own person" and because the monetary reward, although quite substantial, was not worth the effort to improve specific skills.

Of course, many might argue that in both instances the severely handicapped girl and the teenage son would perform if only the reinforcers were made different or more powerful. For the severely handicapped student one might, for example, have used a previous procedure of withholding food during meals to increase the reinforcing value of food during periods of classroom instruction. The amount of money offered to the teenager might have been increased tenfold. In both cases, however, the skills learned and performed might not have seemed important to either youngster, and likely not perceived as substantive additions to their behavioral repertoire. Maybe both youngsters have told us, in different ways and for diverse reasons, that they wanted to have some input in what they are to do and to learn.

We are not implying that we should abandon all of our instructional programs for severely handicapped students nor all of the behaviorally based procedures which are used as important aspects of the teaching process. We are strongly suggesting, however, that instructional programs for the severely handicapped move in a direction that allows the students to grow and develop in ways they perceive as important. In addition, they should be viewed as self-directing and purposeful human beings, rather than mere objects of external manipulation, no matter how well-meaning this manipulation appears to be.

THE RIGHT TO CHOOSE

It is not surprising that there is a dearth of published studies investigating choice among the severely handicapped population, or, for that matter, among any population of handicapped individuals (Holvoet, Brewer, Mulligan, Guess, Helmstetter, & Riggs, Note 1). As already discussed, the current technology has been directed towards identifying the skills severely handicapped persons ought to be taught and then tightly controlling the instructional environment where the acquisition of such skills will occur. Ironically, the one exception to the issue of choice is the frequently used reinforcer selection process with which we systematically determine those objects and events that are most salient to the severely handicapped person, and, hence, more likely to assist us in controlling the instructional environment and the performance of the learner.

Conspicuously missing is the same intense effort to permit severely handicapped persons a reasonable degree of choice in what they would like to learn, or even the method in which the skill might be taught. Again, as the controller, we always assume to know what is best for our severely handicapped students. We presume to know what will enable them to function better in our world, but then are dismayed when they 1) do not learn our chosen tasks or do so slowly, or 2) fail to demonstrate competence of presumably learned skills in other settings or situations. The latter case, a failure to generalize, is typically followed by additional instructional procedures to promote the display of skills in other settings, contexts, and with other persons and materials. We never consider the possibility that generalization did not occur because the severely handicapped person found our carefully chosen instructional objective to be unuseful—when removed from the tightly controlled instructional environment, our student chose not to engage in the behavior. All of us have been in situations where we have been required to learn certain skills which we quickly "forgot" or disregarded once removed from the reinforcer (and punisher) that controlled our initial skill acquisition. We, in effect, choose not to use or display our newly learned skills when freed of the imposing contingencies that were present during the instructional process. It might just be possible that severely handicapped students sometimes choose to display that same type of self-direction, and that our selection of skills for them to learn might not correlate with their own perceptions of what is useful or desirable.

Options for Teaching Choice

One can identify at least two types of situations where the opportunity to choose should be made available to severely handicapped students. The first type pertains to those severely handicapped students who could make a choice if only they had the opportunity to do so. The second situation is more complex because it involves more than making choices. It refers to the opportunity for the student to engage in spontaneous behavior which may or may not be directly associated with structured training.

Structured training options are merely a format for allowing severely handicapped students the opportunity to select from a specified number of skill areas what they would like to learn. Practically, this should not be difficult for the teacher and other service providers. The students are given the option to choose the skills they would like to learn from a list of IEP goals. These might include self-help skills (e.g., learn to make the bed, put on makeup, or iron clothes), leisure skills (e.g., bowling, basketball, or swimming), or vocational training skills (e.g., assembling electronic parts, washing dishes, or doing janitorial work). When certain skills are learned, new choices are provided to the student, consistent with the IEP objectives and in consideration of what has been learned. A failure to learn would require a readjustment of the instructional procedures or the option to choose another activity, as all of us would do. Other options in the instructional process might involve allowing the student to choose where the instruction is to be provided (e.g., classroom or community), with whom, if group instruction is required, or even when, in some cases.

To some, the prospect of providing severely handicapped persons with the opportunity to choose even limited instructional activities would seem inconsistent with the ultimate purposes and outcomes of special education. What if the learner chooses to learn skills that are not appropriate to their chronological age (e.g., a 16 year old who prefers to play in the sand box rather than participate in a dressing program), or what if they choose to do nothing at all?

This reasoning fails to recognize that choice is not an all-or-nothing decision. Certainly we are not proposing that severely handicapped persons (or anyone else) have total control of what they want or do not want to do, or how they do it. We are saying that, within specified limits, severely handicapped persons should have the opportunity to choose what they want to learn, but current practices do not usually acknowledge this option. Our position is that the ability to choose and to have some control over one's own destiny is one of the most important skills that can be imparted to severely handicapped students, or to anyone else for that matter.

We must also realize that choices selected by severely handicapped persons, even within a limited selection of options, might not always concur with what we think is best for them. Failure, however, to appreciate their right to choose is to perceive them possibly as less worthy, or even as somehow less human than the rest of us. All of this might seem unreasonable or impractical, perhaps because we do not orient ourselves in the direction of choice where severely handicapped students are concerned. Our perceptions of severely handicapped students, partly as a result of the controlling technology we use in their education and treatment, have diminished our ability to see them as individuals capable even of making a choice, let alone the right choice.

The Choice to be Spontaneous

"Look at me."
"Good looking."
"Hands in lap."
"Nice sitting."
"Say, ball."
"Good talking."
"Jason, put the ball back."
(Teacher turns away for 10 seconds.)
"O.K. Jason, hands in lap."
and so on.

Instructional control is being established, Jason is learning to respond on cue. The imitation of "ball" is accelerating, as are the hands-in-lap and sitting behaviors. Jason, in effect, is becoming more compliant with each instructional session. He no longer tries to greet persons walking by during training, he does not get out of his chair to look out the window, and he has almost stopped throwing the ball across the room. Jason is performing near criterion, and such mastery will contribute to the attainment of his IEP goals.

Jason, and others like him, were popular subjects for research studies utilizing behavioral technology—easily controlled, limited interfering behavior. Six years later, Jason is not much beyond imitation. He rarely uses the few (word) labels he has learned. Those who knew him years ago say he has really shown improvement because he is so very compliant. Assuredly, he is not the mischievious boy who previously tantrummed, avoided eye contact, and occasionally defecated out the window. Our tightly controlled instruction assured that Jason would acquire some skills. But what is the consequence on his overall development? Are these skills we have carefully taught demonstrated outside of our controlled contingencies? What of spontaneous behavior?

Jason is not a special case. Nor is Dean, a deaf/blind adolescent who ambulates only when given physical guidance. Regardless of the 'motivating' circumstances around him, Dean will stand and wait for his cues. Nor is Tim, who will stand in front of his chair in the lunch room and wait for the sign "eat" before he will sit down. Regardless of how hungry he is, Tim will stand while others complete their meals and even will miss his meal if not given the appropriate cue.

Do these examples reflect just the failure to fade instructional cues to the natural environment, perhaps representing an incomplete application of behavioral technology? Possibly, in many instances. They may also suggest, however, that the inevitable outcome of tightly controlled instructional programs over time restricts individual spontaneity. It may be that tightly controlled instruction programming over the long term teaches severely handicapped persons to engage only in those behaviors that have been included in their instructional regimes; as if they have learned to respond only when being taught under highly structured training conditions. Accordingly, skills learned during instruction, while positive from the teachers point of view, may give way to a more negative outcome for the learner, i.e. *instructional dependency*.

How can teachers provide systematic instruction to severely handicapped students yet allow for maintenance and encouragement of spontaneous behavior? Some behaviorists might argue that spontaneous behavior is an illusion, that all behaviors are reflexive or in direct response to external stimuli. The purpose of education and training for the severely handicapped student, from this perspective, is to accelerate the conditioning process, thereby allowing the student more options to behave through an expanded response repertoire. This type of determination avoids any reference to mental states or attributes that attempt to explain behavior beyond the relationship between the person and the environment (cf. Skinner's *Beyond Freedom and Dignity*, 1972). Accordingly, internally-derived behavior, including spontaneity as well as other subjective experiences, are sometimes considered both unscientific and unnecessary.

As pointed out by Heshusius (1982) this type of reasoning is a direct result of the mechanistic view of the world that has pervaded the social sciences from Newtonian physics. "In the mechanistic view, the student is seen as a reactive/passive organism, just as matter in Newtonian physics was seen as passive, put into motion by the force of gravity" (p. 8). Heshusius further points out that the mechanistic model has been left behind in physics, but still persists in the social sciences, including special education.

ARE WE TRAINING TECHNICIANS OR TEACHERS?

We have come a long way in developing more sophisticated procedures for monitoring skill acquisition among severely handicapped students. We have formulas for projecting trend lines and anticipating completion dates for "criterion," and the flexibility to adjust and readjust the instructional programs when student progress is slow or absent (cf. Sailor & Guess, 1983). We spend considerable time in preparing teachers to read graphs and to use these data as an integral component of the educational process. We pride ourselves in how advanced our instructional technology is when compared to other areas of special education, or even when contrasted with regular education. We have, in fact, fostered an elitism that nicely separates us from them, and which gives our teachers a certain "scientific advantage" over the less enlightened special education teachers. This advantage is offered as our advanced instructional technology coupled with a system to quantify child progress.

It might well be, however, that in the endeavor to develop and promote our instructional technology we have altered the role of teachers to that of "educational technicians" (Heshusius, 1982). In our zeal to use the inimitable behavioral approach, have we lost sight of our original objectives of improving the quality of life for our severely handicapped students? Are our teachers displaying the same lack of spontaneity and self-direction that we might be seeing in the recipients of their instructional efforts?

We propose that teacher education programs for severely handicapped students initiate a thrust to bring the child back to the center of the educational effort. The teacher training programs should include parts of the prominent behavioral technology while recognizing the limits of its implementation.

Selection of Educational Goals We need to view development as a process encompassing the lifespan of the severely handicapped individual. This assumes that teachers and other instructional personnel must identify the educational goals and objectives that reflect the particular developmental level of the severely handicapped child, and the skills needed to maintain their steady growth towards independence and self-fulfillment. This is obviously a subtle and potentially misunderstood recommendation to the extent that it conflicts, philosophically, with a concept that most of us have strongly embraced—the "criterion of ultimate functioning" (Brown, Nietupski, & Hamre-Nietupski, 1976).

The criterion of ultimate functioning has the most desirable attribute of assuming that programming for the student should be directed towards the enhancement of skills necessary for a more productive future life. Our concern with the criterion of ultimate functioning is that it presumes teachers and others have the wisdom and foresight to determine for the student what *ultimately* will be *functional* (see Brinker, present volume).

As a procedure for identifying educational objectives and goals, the criterion of ultimate functioning lends itself easily to both operational definition and instructional implementation. One surveys subsequent environments or tasks, identifies skills necessary to perform in the environments, and then selects from a large assortment of task-analyzed programs those that would best meet the learner's instructional needs. The criterion of ultimate functioning thus assumes, on an a priori basis, that our selection of long-term objectives will be consistent with those of the student—an assumption that, again, places us in the position of well-meaning cultural designers (cf. Nolan, 1974, for a critical analysis of the use of behavioral technology to design cultures). This view is inconsistent with our proposed thesis that education for severely handicapped students should be considered as a process that produces more, and not less, self-directed behavior.

Our position is that the educational process for severely handicapped students should lead to the criterion of ultimate *opportunities* in functioning, as determined substantially by the student. Many readers are of course saying, "Nice idea, but it is not very realistic." After all, how can individuals with such severe intellectual impairments reasonably make the appropriate decisions in their educational process? They are, in fact, too mentally retarded to make the right choices, if they even choose at all. Our argument is that the current instructional philosophy does not allow us the opportunity to find out how severely handicapped persons might choose to develop. We are too preoccupied with programming the student according to our own perceptions of what is good, successful, and important.

Our recommendation is that education for severely handicapped students and the preparation of their teachers should concentrate on the development of critical skills that are consistent with the student's developmental level and that provide a solid basis for the later acquisition of higher level skills. The perceived need to develop critical skills that would be effective across tasks and environments has been discussed earlier (cf. Guess & Noonan, 1982) and elaborated on by Voeltz and Evans (1983) in reference to the potential for collateral effects.

> By whatever name, the concept of interrelated behaviors is a promising one, since severely handicapped learners simply would not have the time to learn all necessary skills if each behavior had to be acquired separately through direct instruction (Voeltz & Evans, 1983, p. 5).

It is our position that the development of critical skills will not only enhance the response repertoire of severely handicapped learners, but in the long run will provide them with a greater opportunity for self-directed behavior. We acknowledge at the outset that the problem of identifying critical skills may be due to the preoccupation with teaching multiple splinter skills. It may be, however, that severely handicapped learners themselves can help us to identify critical skills if we became more perceptive in observing their often subtle attempts to display emerging behaviors.

An example is in order: As Rachel is rolled to her wheelchair, her feet brush across a pillow; she extends her legs and pushes against the soft foam. This motor action deters Rachel from the task-analyzed sequence, and the supine to right side rolling pattern is marked incorrect (−) on the data sheet. Her well-trained teacher quickly pulls Rachel away from the pillow and continues the correct rolling sequence. Could this teacher attend to Rachel's initiated movement by moving her legs toward the pillow and helping develop further movements to foster Rachel's spontaneous exploration? The appropriateness of such diversion from the task-analyzed sequence is dependent on the knowledge of Rachel's overall functioning level and the relationship of this behavior to her repertoire of skills. Our contention is that such "off task" behavior can be explored and integrated within Rachel's objective at that moment. Then within that natural occurrence it could be easily worked into the desired rolling pattern. Thus, behavioral technology becomes a tool utilized within the identified sequences of both the student's spontaneous and elicited behaviors.

Teaching to the Data Sheet The instructional technology of special education, partly by design and to some extent by misapplication, has possibly served to distract teachers from observing nuances of child behavior. These subtleties might provide insights into emerging critical skills that should be further expanded as essential benchmarks in the developmental process. The zeal for precision teaching may have inadvertently directed our attention away from the severely handicapped learner—towards the means rather than the ends of the educational outcome. As discussed earlier in this chapter, teachers (and teachers to be) are often evaluated on how well they implement instructional procedures during training and to the extent that the learner remains on task. The regime, as prescribed by the written program and the data sheet, tends to supercede the teacher-child interactions. We, in effect, tend to evaluate teacher technique per se, rather than teacher adaptability and flexibility to ever changing student behavior. Post-session analyses of student behavior are then made via the permanent product of marks (correct, incorrect, etc.) on the data sheet. We then point with pleasure to our empirical decision making process that reflects program changes made on the graphed data. To this end, individualized instruction is assumed to have occurred. Perhaps such data support the conclusion that instruction has occurred, but it is our opinion that such instruction is *not* individualized. In many instances the teacher is oblivious to or disregards those behaviors that are contrary to the programmed objectives. Because we have assumed that severely handicapped learners are passive agents of our actions rather than contributing members of the educational process, teacher training institutions perpetuate such rigid instructional methods. We have in many respects denied opportunities for severely handicapped students to assert their own uniqueness by providing them with well-trained technicians, rather than teachers. To provide suggestions for better preparation of teachers of the severely handicapped is to acknowledge the limitations of behavioral technology. Such an acknowledgement allows us to assert some new principles which may be rejected by many, not because of their intent but because of their limited data base.

PRINCIPLES FOR TEACHER TRAINING

The first principle, and possibly the most important one, is that teachers must recognize that severely handicapped learners may also have their own agendas in life—that they are individually unique persons who, in spite of their handicapping conditions, possess those motivations, needs, emotions, and purposes that we so strongly associate with humanness. They are not to be perceived as objects to be manipulated, shaped, or molded solely to adapt better to our society or to satisfy our own designs. (In fact, a moments reflection might lead to quite the opposite conclusion.)

The second principle is that teachers of severely handicapped students should be prepared to enhance and guide the development of their students in areas that might frequently extend beyond their identified instructional objectives and goals. This principle implies that teachers and others must be better trained to observe children for indications of subtle, often fleeting, but important emerging skills. Observations of teachers in classroom settings indicate that they frequently miss opportunities to expand or even reinforce new behavior. This occurs because teachers are not prepared to identify and appreciate important emerging behaviors that occur beyond the context of the written programs.

According to Bricker and Schiefelbush (1984) important communicative behaviors evolve from reciprocal exchanges between caregivers and infants.

Early communication intervention begins with the interactive functions in reciprocal caregiving activities. Such intervention procedures should stimulate the amount and kind of natural contingencies that control normal child-environmental transactions. Similarly, severely handicapped students require teachers who are sensitive and respond directly to student-initiated communication(s) as they occur in daily interactions. Such spontaneous and natural interactions will affect the social and communicative behavior of the student and can easily be incorporated within an instructional framework.

We suggest that teachers of the severely handicapped respond with more sensitivity in all their educational interactions. We are essentially arguing for the need to train teachers to capitalize on opportunities of student-initiated behaviors. We acknowledge the similarity of this procedure to incidental teaching techniques. A major difference, however, is that incidental teaching is most typically prearranged such that the environment is better structured to set the occasion for the desired responses. The use of "opportunistic teaching" advocated here focuses on behaviors that more appropriately reflect student initiated actions and that may or may not be directly identifiable with specific environmental cues prearranged by adult caregivers.

It is our position that *technicians* can be taught to follow carefully prescribed instructional programs. With instruction, technicians can be prepared to systematically and accurately move a severely handicapped learner towards successful completion of an identified educational objective. It is a *teacher*, however, who can provide a broader approach to the educational process by modifying the instructional environment to enhance untargeted emerging skills that demonstrate movement toward more complex and adaptive levels of functioning. Teaching these skills will require a more thorough orientation to the developmental process and, equally important, require the sensitization of teachers to be better observers. Using videotapes of teacher-student interactions during instruction might be one method of helping teachers respond to student initiated behavior during training. More systematic measures of teacher performance competency in reacting to student initiated behavior would provide another method of preparing teachers in this area.

The third principle is that teachers should orient to the importance of spontaneous behavior and choice as major educational outcomes. At all levels of instruction, from infancy through secondary level classrooms, teachers should be directed to implementing instructional programs that allow for, and teach, severely handicapped learners to make choices and to engage in spontaneous behavior. This principle may require a new "mind-set." We are, after all, advocating an orientation that often conflicts with the basic premises of behavioral psychology, and one that views severely handicapped learners in a different manner. Preparing teachers to view severely handicapped learners as self-directing individuals may be the most difficult obstacle faced yet in this area of special education. It will require us to accept a more holistic approach to the education of severely handicapped learners and to appreciate the dynamic interactions between student and teacher in the instructional process.

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CHAPTER 13/
THE CONSEQUENCES OF BIAS IN STUDIES OF LIVING ARRANGEMENTS FOR THE MENTALLY RETARDED ADULT[1]

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- **Why study living arrangements?**
- **Bias and its consequences**
- **Coping with bias in scientific studies**
- **Unbiased studies of the effects of living arrangements on the mentally retarded**
- **Are natural experiments enough?**
  - Could all mentally ill people be treated more effectively in community-based programs?
  - Could institutional care be improved?
  - Could alternative care be improved?
  - How can alternative care programs best be implemented?
  - Which features of institutional and alternative care programs are responsible for their positive effects?
- **Summary: The common ground of science, social policy, and clinical practice**
- **References**

More can be learned from considering how and why one might study the effects of different living arrangements upon mentally retarded people than from reviewing what has so far been found by such studies. Most of what has so far been found is scientifically uninteresting and provides little guidance for improving living arrangements because the methods used to

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find it are biased. It is time to ask why we want to know about the effects of living environments on mentally retarded people, and how we might come to unbiased knowledge about it. Without unbiased information, sound planning is extremely difficult.

WHY STUDY LIVING ARRANGEMENTS?

Many nations provide living arrangements for some of their mentally retarded citizens. Their justifications vary, but whatever the reasons, their practices occasionally come under scrutiny, as they have in the United States in recent years. Whenever this happens, governmental and private agencies want to know whether the official justification for special living arrangements is being fulfilled. If a nation justifies its special arrangements for the retarded as ways to prolong and enhance their lives, there comes a time when it is necessary to determine whether the special living arrangements do prolong and enhance lives of retarded people. If a nation justifies its special arrangements as a way to habilitate retarded people so that they can return to more typical living arrangements, there comes a time when it is necessary to determine whether the special arrangements habilitate retarded people. It can be argued that even before necessity arises, society should check to see whether the special arrangements for which it pays are providing fair returns on the investments. Thus, there are economic and social justifications for studying the effects of various living arrangements upon the mentally retarded person. The reasons are to protect taxpayers and recipients of the services, and to provide factual bases for social policy.

People who provide special living and care arrangements for the mentally retarded often want to know how effective the arrangements are or how to provide more effective arrangements. Sometimes simple pride motivates care providers to search for the most effective way to do their jobs. Sometimes lack of resources or budget cuts motivate studies of alternative living and care arrangements. Sometimes changes in social policy motivate clinical studies of living and care arrangements. For example, the deinstitutionalization movement has raised questions about the relative efficacy of total institutional care compared to community-based care. Whatever the motivation, the methods for clinically justified studies are often different from those with social justifications. Thus, the methods for evaluating whether the special programs of an entire state are habilitating mentally retarded people will differ from the methods for determining whether the medical practices of a particular institution are prolonging the lives of its residents.

In addition to social policy and clinical reasons for studying living arrangements for the mentally retarded, there are scientific reasons. While no scientist would create special living arrangements just to answer a scientific question, many studies of existing service systems have been justified scientifically, thereby treating already established special living arrangements for the mentally retarded as natural experiments. Thus, there have been studies of the effects of institutional and other living arrangements on intellectual development (Balla, Butterfield, & Zigler, 1974), motivation (Zigler & Butterfield, 1968), personality (Zigler & Butterfield, 1966), and social competence (Klaber, Butterfield, & Gould, 1969). Almost all scientific studies of special living arrangements have sought to answer specific forms of the general question, How does the environment influence behavior? Studies designed to answer this question need not focus on mentally retarded people nor upon special living arrangements. Studies with emotionally disturbed, deaf, blind, and normal people, as well as laboratory studies of various animals, are as scientifically pertinent as studies of the mentally retarded person. Pertinent environmental variations for scientific study include teaching methods, language experience, perceptual stimulation, and nutritional experience as well as living arrangements. Because the scientific reasons for studying special living arrangements for the mentally retarded are usually broader than the social and clinical reasons, the possibility of bias in such studies is always a problem for the scientist. Bias is sometimes a problem while it is sometimes quite unimportant to those who study special living arrangements for social and clinical reasons. It may or may not defeat the purpose of a clinically or socially motivated study.

BIAS AND ITS CONSEQUENCES

The chief source of bias in studies of special living arrangements is that complex social, administrative, and clinical forces combine to select who enters the arrangements. Such selection biases create interpretative problems. When people who have lived in a special environment are found to differ from others, the question is whether the difference can be attributed to the living arrangement, to the characteristics of the people who were assigned to the living arrangement, or to an interaction of the arrangement with the people's characteristics. Unless people have been assigned randomly to the environments that are compared, no clear interpretation is possible. Subsequent differences between people assigned nonrandomly may have existed before the assignment or they may be the results of the living environment or of an interaction between the environment and their pre-existing characteristics. The lack of random assignment always defeats the scientific purpose of comparing people in different living environments.

Scientific studies are defeated by a lack of random assignment because the focus of such studies is upon the effects of different environments. Unless people are randomly assigned to environments, it is unreasonable to assume that they are comparable people, and unless they are comparable when they enter the environments, later differences between them cannot be attributed to those environments or any other known condition(s). This is true even when the effects of different environments are hypothesized to depend upon the characteristics of the people experiencing them. Such interactional hypotheses require the random assignment to all studied environments of people from groups that differ in known ways *in advance of the assignment*. It is not sufficient to identify people who have been nonrandomly assigned to different environments and to decide which people are comparable by some assessment procedure. The reason is that our assessment procedures are not able to validly detect all pertinent sources of variation among people. After-the-fact matching is not a satisfactory alternative to random assignment when the focus is on either main or interaction effects of environmental variables.

Some studies done for social or clinical reasons are not rendered invalid by selection bias. For example, if the question is whether people who receive care in a special living arrangment advance to the point of being able to subsist outside the arrangement, then selection bias is irrelevant, because the question is about people who are selected for the arrangement. A service system might well want to answer this question. However, if the service system was interested in the more specific question of whether advances resulted from care given in the living arrangement, then it would need to arrange random assignment to living arrangements. If the question to be answered by studying a living arrangement pertains only to the people who live there at the time of the study, then bias is not a problem, because the effect of bias is to compromise generalization of conclusions to people not studied.

COPING WITH BIAS IN SCIENTIFIC STUDIES

Despite the fact that random assignment to living arrangements is the only way to eliminate selection bias, many scientific studies without random assignment have been reported. Some of these studies employ designs intended to minimize the effects of nonrandom assignment on the interpretation of their findings. For example, Butterfield and Zigler (1965) studied the effects of two institutions from the same state and having identical admission policies. The authors had observed marked differences in the management of children in these two facilities, and they expected that one institution would heighten the needs of its retarded residents for social reinforcement more than the other institution. The data were consistent with the hypothesis: Children from one institution responded more to social reinforcement than children in the other institution. The critical interpretative question is whether the difference in responsiveness should be attributed to differences between the living arrangements or to differential assignment of retarded people to the two arrangements. Had the assignment been random, this question would be irrelevant, so the question is whether the existence of identical admission policies is equivalent to random assignment.

The two institutions studied by Butterfield and Zigler served different halves of the state in which they were located. Therefore, while their admission policies were described as identical, the institutions drew from different populations. While both halves of the state contained large urban areas, one half was more rural than the other, and the other half contained a greater density of highly affluent people. Other research has shown that the dependent measures employed by Butterfield and Zigler are influenced by socioeconomic background (Balla, Butterfield, & Zigler, 1974). Therefore, it is questionable whether the finding of greater responsiveness of social reinforcement can be attributed to the characteristics of the different living arrangements, even though the admission policies of the two arrangements were formally identical. Studies that compare children from different institutions are less likely to suffer from gross selection bias than are studies that compare institutionalized and noninstitutionalized children. Thus, the study by Butterfield and Zigler represents a methodological advance over studies that compared institutionalized and noninstitutionalized people. Still, only random assignment could have removed all question of selection bias in their investigation.

Klaber, Butterfield, and Gould (1969) reported results that seem to bolster the inference of Butterfield and Zigler (1965) that the depriving management style of one of their institutions heightened social motivation. Klaber et al. (1969) studied children from the depriving institution studied by Butterfield and Zigler. Some children were transferred to another living arrangement, and some remained in the depriving institution. The living arrangement to which children were transferred was judged in advance to manage children in such a way that their motivation for social reinforcement would be less than that of the children who remained in the original institution. The data showed that children in the new institution were less responsive to social reinforcement than those who remained in the original institution. Combining this outcome with the finding of Butterfield and Zigler seems to strengthen the conclusion that the original institution created greater needs for social reinforcement, since children in that institution were more responsive to social reinforcement than children in two other institutions, both of which were judged to have more nurturing management procedures, and since the children studied by Klaber et al. were all admitted originally to the same institution. No selection bias could have operated at the time of original admission.

While selection bias could not have operated when the residents studied by Klaber et al. were admitted to their original institution, it could have operated at the time of transfer to the other institution. Children were transferred in order to bring them nearer to their families, so that those who remained in the original institution came from one area of the state and those who were transferred came from another area. As in the study by Butterfield and Zigler, the socioeconomic characteristics of the areas were different, and as in that study, the children who were less responsive to social reinforcement came from an area with a higher socioeconomic status. Moreover, the study by Klaber et al. was designed after the decisions about who to transfer were made. This necessitated after-the-fact matching of children who were not transferred with those who were. Such matching is not a satisfactory substitute for random assignment (Kiesler, 1982). The question remains about the comparability of the two groups in the study by Klaber et al. This same question remains about the much larger study by Klaber (1969).

Even though random assignment to living arrangements is the only way to insure that differences among people in the arrangements are due to their living conditions and not to pre-existing differences in personal characteristics, the vast majority of studies of living arrangements have used nonrandom assignment. The temptation is great to interpret these studies as showing that living arrangements have different effects on mentally retarded people despite the possibility that their results stem from various selection biases. One way to justify such interpretation is to note that several studies of a particular effect (e.g., heightened social motivation) have yielded a coherent pattern of results and have different sources of bias. The logic is that if similar findings emerge from studies with different sources of bias, bias must not account for the results. This logic is compelling only when it can be shown that some of the biases do not influence the dependent variables studied. Unfortunately, not enough is known about any dependent variable used in studies of living arrangements to be confident that any source of bias is irrelevant, and usually an analytic view of the sources of bias is not available. Moreover, since the central hypothesis of such studies is that environmental variations influence behavior, and since we cannot know all about the environmental experiences of any group of people before they enter a living arrangement, we can never satisfy the conditions needed to evaluate the logic of disregarding various sources of bias when a group of studies with different biases converge upon a single conclusion.

Mentally retarded people who are admitted through normal procedures to a special living arrangement are a biased sample of the population of mentally retarded people. This means they are unsuitable subjects for studies which compare such living arrangements. It does not mean that every study of retarded people in special living arrangements is scientifically meaningless. Thus, people who have been admitted nonrandomly to one facility can be randomly assigned to each of several other facilities or experimental conditions, thereby allowing unbiased study of the effects of those facilities or conditions. Using this approach, generalization of results to the entire population of mentally retarded people would not be possible. Similarly, whenever one can systematically assess the prior living conditions of a group of people assigned nonrandomly to a particular living arrangement, he or she can study those people while they are in the special living arrangement in order to assess the effects of the prior arrangement. As with the random assignment of people in a living arrangement to different conditions, the population to which one can generalize when comparing subjects from different prior arrangements is restricted to people like those admitted to the prior arrangement. The results for that population are unbiased as long as one does not try to establish an interaction between prior living arrangements and present living arrangements. A study by Zigler, Balla, and Butterfield (1968) illustrates the relevant issues.

Zigler et al. (1968) studied changes in social motivation among children who had come to an institution from different preinstitutional backgrounds. Preinstitutional background was assessed with an objective scale applied to information garnered from social histories (Zigler, Butterfield, & Goff, 1966). Zigler et al. found that children from less supportive family environments had greater needs for social reinforcement shortly after institutionalization than did children from more supportive family environments. Moreover, children from less supportive environments showed marked decreases in social needs over three years of institutionalization, whereas children from more supportive environments showed very small changes in their social neediness. It is safe to conclude from these findings that preinstitutional social deprivation heightens need for social reinforcement, and that children with heightened needs become less needy the longer they are institutionalized. One necessary caveat is that these conclusions may not apply to all children who have depriving home environments. They may only apply to those who have depriving home environments *and*, for whatever reasons, are subsequently placed in a particular institution for the mentally retarded. Another necessary caveat is that the source of the decrease in need for social reinforcement is unclear. It might simply be aging, it might be the fact of removal from the original environment, or it might be due to some positive feature of the institutional environment. Given these qualifications, the results can be taken as unbiased.

During the discussion of their results, Zigler et al. noted that their pattern of findings differed from that of a similar investigation in another institution for the mentally retarded (Zigler & Williams, 1963). In an effort to reconcile these findings, Zigler et al. noted that the two institutions appeared to differ in how supportive they were of their residents, and the investigators suggested that preinstitutional environment interacts with institutional environment to create different sorts of changes in need for social motivation. This hypothesis seems reasonable, but the pattern of results which suggested it could be due to selection bias. That is, the two institutions may well have had different selection criteria, and these criteria could have dictated the pattern of results.

When studying the effects of preinstitutional environments, the appropriate use of different institutions is to determine the extent to which particular findings can be generalized to people admitted to all institutions for the retarded. If preinstitutional variables are found to have the same effect across several institutions, then one can conclude that the preinstitutional variable is an important one among people who are admitted to institutions for the retarded. However, if a preinstitutional variable has different effects across institutions, the findings are not interpretable, since they may be due to selection bias. Since there is a third study showing that the nature of the effects of preinstitutional environment varies with the institution studied (Balla, Butterfield, & Zigler, 1974), the appropriate conclusion is that preinstitutional living environment as assessed by Zigler and his collaborators has no demonstrated general effects on social motivation.

Bias in the assignment of mentally retarded people to special living arrangements has several effects. It invalidates comparisons among different living arrangements unless the bias is prevented by random assignment. It limits the generality of conclusions from studies done in particular institutions, unless the results of those studies are shown to be general across people in different institutions. As a rule, this latter result is more likely to be observed when the people who live in a particular institution are randomly assigned to different living arrangements than it is when people who live in a particular institution are divided according to their preinstitutional experience.

The consumer of biased research is in the same position as the consumer of a poisoned meal. It makes no difference that every dish may have a different poison. None of the dishes should be consumed. Bias is like poison, except that there is no antidote for bias. There is only prevention, in the form of studies that are unbiased.

UNBIASED STUDIES OF THE EFFECTS OF LIVING ARRANGEMENTS ON THE MENTALLY RETARDED

Landesman-Dwyer (in press) has reported the only large study of the effects of living environments to which mentally retarded people were randomly assigned.[2] Landesman-Dwyer began by constructing 49 trios of severely

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[2] A much smaller study by Close (1977) also featured random assignment of mentally retarded people to different living arrangements. Its primary independent variables were intensive treatment routines that could have been used in any place of residence. I have been unable to locate any other studies of retarded people employing random assignment to living conditions.

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retarded people (n = 147). The three people in each trio were residents of a single multipurpose institution, and within trios they were matched for sex, adaptive behavior, age, length of institutionalization, and medical and behavioral characteristics. One member of each trio was selected (nonrandomly) by clinical and administrative staff for assignment to a new living arrangement. A second member of each trio was randomly selected for assignment to the new arrangement, and the third member remained in the old arrangement. Baseline data were collected for one year before any residents were moved to a new living arrangement. Outcome data were collected for a year after residents moved from the old to the new living arrangements. The data were derived from observations of day-to-day behavior, standardized ratings of adaptive behavior, and assessments of health. Landesman-Dwyer found small but reliable effects of changed living arrangements. The nature of these effects varied with the behavioral characteristics of the residents prior to their move. Her findings highlight several methodologic issues that are of great importance to future studies of living arrangements for the retarded.

Logically, there are two approaches to studying the effects of special living arrangements. One way is to examine the effects of such arrangements on people entering them from the community. No unbiased approach of this sort has been attempted with mentally retarded people, but 10 unbiased studies of this sort have been conducted with psychiatrically disturbed people. Kiesler (1982) has recently reviewed these studies, and they will be discussed in a later section of this chapter. Another approach is to examine the effects of changing the living arrangements of people who already reside in an institution. Within this latter approach, one can examine the effects of moving from institutional living to community living or the effects of moving from one institutional arrangement to another. Landesman-Dwyer used the latter approach.

Either type of variation with people already in an institution has several advantages over starting with people who reside in the community. The chief advantages are that any variance due to environmental differences when the study begins will be minimized by the fact that all subjects will have been in the same environment, and it is far easier to collect baseline measures on a large group of people when they are congregated together. There may also be some disadvantages of this approach. If institutional living has major adverse effects on mentally retarded people, and if these effects are difficult to overcome, then studying people who have already resided in an institution for a long time may not reveal the effects of new living arrangements, because the people studied will be resistant to the influence of the new environment. This could be especially true when examining the effects of moving from one institution to another. A related disadvantage could result from the fact that people who have resided in an institution will be older than those who are coming to one for the first time. If the effects of living arrangements are greater on younger people, starting with people already in an institution could reduce the likelihood of observing effects of living arrangements. Landesman-Dwyer's subjects had a mean age of 35 years and a mean length of institutionalization of 22 years. Whether these facts reduced the size of her observed effects is impossible to determine now, but it could be determined by other unbiased studies in which age and length of institutionalization at the time of transfer were varied. However, varying age and length of institutionalization assumes that people of different ages and lengths of residence are comparable in all other respects. That is, it assumes that age and length of institutionalization are not confounded with other factors. It is unreasonable to assume unconfounded comparisons across age and length of institutionalization if admission policies have changed over time or if the policies are designed to make it easier to admit people of certain ages. In this country, admission policies have changed dramatically in recent years, and are now designed to militate against the admission of younger people.

Despite the disadvantages of beginning with people who have already resided in an institution, that seems the most reasonable approach in future studies. Many more retarded people are being released from institutions than are being admitted to them, so that studying large groups of newly admitted people will be impractical and there will be relatively less clinical and social policy interest in such studies. Policy makers have already decided to keep admissions down, but they remain interested in the question of the desirability of different placements for retarded people who are already institutionalized. Moreover, Landesman-Dwyer's study established that there is an overwhelming methodologic advantage to studies of people who are already in a congregate living facility. The advantage lies in the relative ease of collecting baseline data prior to moving residents to different living arrangements.

Landesman-Dwyer's cluster analyses of her baseline data revealed five distinctly different groups of residents. These groups responded in different ways to their new living arrangements. Had Landesman-Dwyer lacked the opportunity to collect her baseline data, her findings would have been far less meaningful, because she would not have had any pre-move basis for segregating her subjects into groups. Her findings illustrate the generally useful principal of grouping subjects according to measures that are directly related to the dependent measures employed in a study. Students of learning and memory have known for some time that their experiments have greater power and meaning when their subjects are grouped on empirically relevant variables. Thus, as early as 1969, Belmont and Butterfield argued that studies of mentally retarded persons' memories are more powerful and informative when subjects are grouped according to their memory characteristics rather than according to some gross factor such as Mental Age or an IQ score. Landesman-Dwyer's findings indicate that the same is true for studies of living environments.

While Landesman-Dwyer was able to define subgroups of retarded residents prior to changing their living environments, she did not take subgroup membership into account when assigning subjects to environments. That is, her matching within trios was based on age, sex, etc., rather than on baseline measures. In future studies, residents should be divided into subgroups according to baseline measures or some other directly pertinent indices before they are randomly assigned to living arrangements. However, one must expect regression to the mean to attenuate or exaggerate some differences between pre- and post-move measures when pre-move subgroups are formed from measures that will also be used to assess the effects of a new environment. Landesman-Dwyer's findings indicate that such regression effects are not great when one has a large amount of baseline data to use for the subgrouping of subjects. Even further reduction and possible elimination of regression could be obtained by using one set of baseline measures for classification purposes and a subsequently collected set of baseline measures for comparison with post-move measures. Using this procedure, regression effects are reflected in the second pre-move measure rather than in the post-move measures alone.

Landesman-Dwyer found no differences between the residents who were moved as a result of clinical and administrative decisions and those who were selected randomly. This does not mean that clinical/administrative decisions are functionally random. If it did, then the prior arguments about random assignment and bias could be dismissed. If clinical/administrative decisions were random, then comparisons among different living arrangements would not be biased by subject selection factors. The clinical/administrative decisions in Landesman-Dwyer's study were constrained by her trios design. That is, these decisions were not based on the retarded people's age, sex, adaptive behavior, length of institutionalization, or medical or behavioral characteristics, because the trios (from which the clinical/administrative selections were made) were matched on these variables. Such constraints do not apply to usual clinical/administrative decisions. The lack of differences between clinically selected and randomly selected residents in Landesman-Dwyer's study does not contradict the argument that selection bias invalidates comparisons among groups assigned by unconstrained administrative/clinical processes.

Landesman-Dwyer observed that the residents who remained in their original living arrangement changed some of their behavior from before to after the move of the *other* residents. It is difficult to judge the extent to which these changes are regression effects, but their occurrence suggests a refinement of the design for future investigations of the effects of moving residents from one congregate living arrangement to another. The refinement should include two groups who remain in the original facility, one group of residents who might be influenced by the move of other residents from the facility and a second group who could not be so effected. To do this in an unbiased way, one would begin by taking baseline measures for purposes of matching subjects. Having decided how many groups were to be studied (say four groups), one would then select groups of subjects (quartets in the case of a study with four groups) who were matched within groups (quartets) on the baseline measures. All four of the residents in each quartet would then be moved within their place of residence. This movement would be random with the restriction that three members of the quartet would be moved to living units from which members in the study were to be drawn at placement time. The fourth member of each quartet would go to a living unit from which no one in the study would subsequently be moved to new living arrangements. Prior to placement, additional baseline measures would be taken. Their purpose would be to allow for regression effects. These additional measures would be used as the pre-move measures in the study of changes in living environments, and they would allow a check on the possibility that different living units within the facility had different effects upon their residents. Following these measures, two of three residents would be randomly selected for placement. Upon completion of the followup, comparisons among the residents who remained in the institution would allow the separation of further regression effects from the effects of remaining in an institutional setting from which other residents had been moved. Other variations on this design are possible, and they share the characteristic of allowing study of the extent to which regression effects occur and the extent to which a living arrangement's effects are determined by the grouping of residents within it. One interesting implication of Landesman-Dwyer's findings is that even severely retarded people may be influenced by changes in the cast of characters with whom they live, and variations on this design would allow evaluation of that implication.

ARE NATURAL EXPERIMENTS ENOUGH?

Landesman-Dwyer found that severely retarded people showed few large behavioral changes when the State of Washington moved them from one living arrangement to another. She viewed this as unsurprising, because both the new and old environments were unstimulating. Officials of the State of Washington built new facilities that were far more homelike than its older institutions. The new facilities met licensing standards that the old ones did not approach, and the new facilities had more staff members per resident. Nevertheless, when the residents were transferred from the State's older institutions to its new facilities, no new programming was provided nor were staff of the new facilities told or trained to behave differently than staff in the old facilities. As Landesman-Dwyer (in press) notes, finding ways to create large behavioral changes ". . . is likely to be more difficult than just building new buildings, meeting Federal licensing standards, and providing more staff to look after things." It follows that researchers who are looking for large effects of different residential arrangements will probably have to do more than study the effects of changes in residential arrangements that just happen to occur in an existing service system. It is not enough to arrange unbiased assignment of retarded people to residential arrangements. One should also guarantee that the residential arrangements are substantially different from one another in the demands and resources they place upon residents. Natural experiments are not enough.

Close (1977) did the only other study in which retarded residents were randomly assigned to living arrangements. In his study, the new living arrangement differed from the old one not only physically, geographically, and in generic programming, but also in specialized programming. The new arrangement provided individualized training programs for its residents. The old arrangement did not. The effects observed by Close seem large compared to those observed by Landesman-Dwyer. This is consistent with Landesman-Dwyer's conclusion that large effects require more than a change in physical environment. Unfortunately, Close's study cannot be taken as affirmation of Landesman-Dwyer's conclusion, because his study confounded changed environments and changed programming. It is impossible to determine whether the difference in magnitude of results between Close's study and Landesman-Dwyer's stemmed from the fact that Close's study involved radical changes in programming, whereas Landesman-Dwyer's did not, or whether the particular environment to which Close's subjects were transferred somehow prompted larger gains than the environment to which Landesman-Dwyer's subjects were transferred.

To sort out the effects of changed environments and changed programming, environmental and programming changes need to be varied orthogonally. Some residents of an institution should receive neither a new environment nor new programming, some should receive new programming in their old environment, some should receive a new environment alone, and some should receive both a new environment and new programming. The environmental and programming changes should be large according to some theory about how such changes should influence behavior, and residents should be assigned randomly to the environmental and programming conditions.

Speaking scientifically, natural experiments fall short in two ways. First, they are plagued by selection bias. Landesman-Dwyer's and Close's studies show that this bias can be prevented, but that prevention eliminates some of the naturalness of the natural experiment. Landesman-Dwyer's and Close's studies also suggest that natural experiments on residential arrangements for the retarded are not enough in the second way, which is that their environmental variations are not sufficiently pertinent to behavior change. Whether more pertinent environmental variation could be made is an open question, and we are unlikely to answer that question if we wait for a relevant natural experiment. Naturalness should be done away with. Close's experiment suggests that programming changes are powerful determinants of behavioral change, but further work is needed to eliminate the possibility that it was environmental change, not programming change that produced Close's results.

There are two ways in which natural experiments are not enough. They provide too little control over selection bias, and they too seldom vary factors that according to theory should have large effects. These are shortcomings from the vantage point of scientists, but in addition to scientific purposes, there are social and clinical purposes to be served by studying living environments for the mentally retarded. Are natural experiments enough to meet the needs of social planners and clinicians? Are they enough if the only modification in them is the elimination of selection bias? Or must social planners and clinicians not only eliminate selection bias but also arrange for theoretically powerful changes in living environments and programming? In other words, are planned experiments the only satisfactory bases for clinical and social action, or will observation of the outcomes of existing practices suffice?

While there are only two unbiased studies of the effects of living arrangements on mentally retarded people, there are 10 unbiased studies comparing institutional care and alternative care arrangements for mentally ill people (Brook, 1973; Flomenhaft, Kaplan, & Langsley, 1969; Herz, Endicott, Spitzer, & Mesnikoff, 1971; Krowinski & Fitt, 1978; Levenson, Lord, Sermas, Thornby, Sullender, & Comstock, 1977; Mosher & Menn, 1978; Pasamanick, Scarpitti, & Dinitz, 1967; Stein, Test, & Marx, 1975; Washburn, Vannicelli, Longabaugh, & Scheff, 1976; Wilder, Levin, & Zwerling, 1966). In each of these studies, mentally ill people were assigned randomly to total institutional care or to community-based alternative care arrangements. Kiesler (1982) assessed the clinical and policy implications of these 10 studies, and his assessments help answer the foregoing questions about the adequacy of natural experiments for clinical and policy purposes. My discussion of implications of these studies is heavily influenced by Kiesler's arguments. Note that it does not matter that these studies used mentally ill instead of mentally retarded people. The issues are the same for the two populations.

The quality of the institutional care provided was high in the 10 unbiased studies of mentally ill people. The modes of alternative care were diverse. In every study, the outcomes for the patients were more positive in the alternative care arrangements than in the institutional arrangements. The outcome measures included psychiatric evaluations, subsequent employment, school performance, maintenance of social relationships, and success at independent living. The costs per day were lower for alternative care than for institutional care. The chief scientific claim that these facts justify is that many mentally ill people who are currently receiving institutional inpatient care could be receiving alternative care that is more effective and less expensive.

Eight of the 10 studies provided follow-up periods during which information was collected about subsequent institutionalization. In every study, the rates of subsequent institutionalization were significantly higher for people who had been previously assigned to institutional care than for people who had been assigned to alternative care. The scientific conclusion is that institutionalization is self perpetuating. Having once been an inpatient, one is more likely to be an inpatient again.

The policy implication of these results is that community-based alternative care should be provided for many mentally ill people who are now being institutionalized. Community-based care should be provided because it is more effective, it is less expensive, and because institutional care is self perpetuating, which further raises the cost to society of treating mentally ill people in institutional settings and which prolongs the recovery of mentally ill people. Now consider some questions these studies do not answer.

Could All Mentally Ill People be Treated More Effectively in Community-based Programs? While the 10 unbiased studies establish that many mentally ill people would fare better in community-based facilities, they do not say whether all mentally ill people would do better in such facilities. The reasons are that not all types of people treated in institutions were included in these 10 studies, and the studies did not seek to find interactions between patient characteristics and type of care. These questions could be answered by further unbiased studies in which different types of patients received either alternative or institutional living. Either existing or experimental living arrangements could be studied, but the chances of finding large effects would be greater if experimental programs were studied. The reason is that experimental programs can be tailored to the purposes of the evaluation and to the characteristics of the patients under study.

Could Institutional Care be Improved? Since these unbiased studies evaluated existing institutional programs, and since they did not study dimensions along which institutions can vary, they say nothing about untried programs. Neither do they say anything about how difficult or easy it would be to change existing institutional programs. These are pertinent questions for policy makers and clinicians alike, and answering them would require planned experiments rather than natural experiments.

Could Alternative Care be Improved? None of the 10 unbiased studies examined more than one type of alternative care, so they provide no evidence about relative effectiveness of the different programs studied. Furthermore, none evaluated any attempt to change or improve an alternative care program. Whether alternative care could be improved is an experimental question that no natural experiment is likely to answer. Both clinicians and policy makers would be interested in the answer.

How Can Alternative Care Programs Best be Implemented? Given that the 10 unbiased studies show that alternative care programs are better for many mentally ill patients, and given that there are too few alternative care programs to accommodate many of the patients who are presently being institutionalized for mental illness, policy makers need to know how to establish new alternative care programs. While something can be learned about this from retrospective reports of people who have established such programs, far more satisfactory answers could be obtained by an experimental program that tested various ways of implementing alternative care arrangements. Again, the clinical and policy questions require an experimental approach. And if such an approach were undertaken, it could answer other pertinent policy questions: *How can one most effectively overcome resistance to closing existing institutions? How can one prevent the economic hardships that might fall on employees and communities of existing institutions if they are closed as a result of increased alternative care arrangements? How can community resistance to the establishment of community-based alternative care programs be overcome?*

Which Features of Institutional and Alternative Care Programs are Responsible for Their Positive Effects? This is the chief clinical question about all complex service systems. It is also the chief question of a policy maker who is interested in minimizing his or her costs or maximizing the return on expenditures. Natural experiments in the form of observations of ongoing programs can provide important information on this question, but definitive information requires an experimental approach in which various features of existing programs are varied in unbiased ways. Despite their random assignment of patients to living arrangements, none of the 10 studies of mentally ill people provide any answers to this question, because all of those studies addressed the molar question of whether complexly different care procedures vary in their effectiveness.

SUMMARY: THE COMMON GROUND OF SCIENCE, SOCIAL POLICY, AND CLINICAL PRACTICE

There are scientific, clinical and policy reasons for studying living arrangements for the mentally retarded. In the introductory remarks it was observed that policy and clinical questions about living arrangements could sometimes be answered by biased investigations, but that scientific questions could never be answered with biased investigations. The argument was advanced that selection bias was unimportant when a policy maker or clinician wanted an answer to the question of how well or poorly services were doing for the people they are currently serving. For such questions, it does not matter whether the outcomes for the clients being served are due to the services or to preexisting characteristics of the clients. It rarely happens that a policy maker or clinician is seriously interested in such questions. Scientists, clinicians and policy makers share a large common interest of wanting to know the particular conditions that promote the welfare and adaptive behavior of the clients in their service systems. The reasons for their interest differ, but they share the desire to have unbiased knowledge, because they wish to know how much the provided services contribute to the welfare of their clients. It follows that future investigations of the effects of living and care arrangements for the severely mentally retarded should result from a partnership among scientists, policy makers and clinicians. The partnership should be devoted to eliminating selection bias from the study of living and care arrangements and to systematically varying living and care arrangements. The approach should be experimental in the sense that it seeks an analytic understanding of the effective elements of current care practices and in the sense that it seeks to understand innovative arrangements that would be more effective than existing arrangements.

If there is any seed of discord in this proposed partnership, it is scientists' desire to test general conceptions. It is possible to execute unbiased studies to analyze existing programs or evaluate innovative programs without testing any theory that would guide extrapolation of the findings to situations beyond the ones studied. Unless a study tests such a theory, it will be of little interest to a scientist, though it could be of immense interest to a policy maker or clinician. Therefore, the challenge for scientists is to judge whether the independent variables they would study for theoretical reasons are interesting enough to clinicians and policy makers to justify their cooperation. The challenge for clinicians and policy makers is to facilitate studies that will not only help to improve the service systems of their immediate concern, but will also contribute to understandings that will make it possible to design systems for other needs, so that every new system will not require extensive experimental analysis.

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CHAPTER 14/

PERSPECTIVES ON METHODOLOGICAL AND RESEARCH ISSUES CONCERNING SEVERELY MENTALLY RETARDED PERSONS[1]

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Recent research with the severely mentally retarded persons:
  A social ecological perspective
The search for the optimal environment
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In the past, severely retarded persons have been studied strictly in terms of their underlying biomedical problems. Medical researchers have attempted to describe and understand the causes, courses, and possible treatments of a variety of devastating diseases such as phenylketonuria (Jervis, 1939), Down syndrome (Lejeune, Gautier & Turpin, 1959), Lesch-Nyhan Syndrome (Lesch & Nyhan, 1964), and a plethora of birth defects and human malformations (Bergsma, 1973), that can result in severe mental retardation. This initial period of biomedical research focus has been successful in elucidating the mechanisms of disease and developing ameliorating strategies to treat the medical aspects of some conditions that are associated with severe mental retardation.

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[1] Except where specified the term severely mentally retarded incorporates the profoundly mentally retarded person.

Biomedical and social researchers have also studied the epidemiology of severe mental retardation. Much effort has been expended in determining the prevalence (i.e., the number of cases of a condition identified in a population at a given time) of severe mental retardation in institutional and community settings (Dingman & Tarjan, 1960). Such studies have shown that the actual number of severely mentally retarded persons greatly exceeded the number anticipated on the basis of the normal distribution of intelligence.

With this biomedical and descriptive perspective as a necessary and valuable foundation, some anthropologists and psychologists have attempted to describe and define the richness of human behavior among severely retarded persons (e.g., Cleland, 1979; Landesman-Dwyer & Sackett, 1978; MacAndrew & Edgerton, 1964; Switzky, Haywood, & Rotatori, 1982). These researchers have described the behavioral characteristics and individual differences that might be relevant for behavioral and psychological development and educational treatment of severely retarded persons.

Based on the measurement of their functional abilities, profoundly retarded persons have been classified into two distinct groups (Miller, 1976): (a) older, less organically damaged persons who have some degree of ambulation, communication functions and self-help skills—the "relative" profoundly retarded, and (b) persons who appear to lack all adaptive behavioral skills and who exist in a fragile medical state—the "absolute" profoundly mentally retarded (see Haywood, Meyers, & Switzky, 1982). The search for functional sub-categories of individual differences among severely mentally retarded persons and how these subcategorical differences may be related to differences in learning and to general questions of aptitude treatment interaction, are in the preliminary phases of study (Switzky, Haywood, & Rotatori, 1982).

Since the 1950s, our conceptions regarding severe retardation have changed radically. Tredgold and Soddy (1956, p. 147) characterized severely retarded persons as follows: "They have eyes but they see not; ears but they hear not; they have no consciousness of pleasure or pain: in fact their mental state is one entire negation." Kirk (1962, p. 86) considered severely retarded children as unable to be trained in self-care, socialization or economic usefulness, and in need of continuing help in taking care of their personal needs. Today, severely mentally retarded persons are viewed as being capable of considerable learning and being able to participate in many social interactions and endeavors (Berkson & Landesman-Dwyer, 1977; Ellis et al., 1982).

The shift in perception of the nature of severe mental retardation has stemmed, in part, from the normalization movement (Grunewald, 1969; Nirje, 1969; Wolfensberger, 1972) focused upon "normalizing" the environments of retarded persons and assuring their rights to education, treatment, and their civil rights in general. Also important was the work of applied researchers, educators, psychologists, and behavior modifiers such as Bijou (1966), Bricker (1970), and Lindsley (1964), who believed that with the correct environmental stimulation and formal training, the behavioral functioning of mentally retarded persons, no matter how intellectually impaired, would show substantial improvement. To the behavior modifiers, people behave in a retarded manner either because they have been taught to do so or because they have not been taught to behave in a more intelligent manner. Thus the primary method for studying and understanding the behavior of severely mentally retarded persons was to develop a process to teach these persons to behave "normally" (Bricker, 1970).

In relatively profoundly and severely retarded persons, operant conditioning methods have been highly effective in increasing adaptive behavior and functional skills in several domains, ranging from general self-help skills, such as eating, dressing and toileting, the deceleration of inappropriate behavior, to such complex functions as receptive and expressive language, sequenced vocational tasks, and academic learning (Matson & McCartney, 1981).

Other researchers working primarily in laboratory settings have done experimental investigations of the learning, perceptual and memory capacities of the severely retarded (Spradlin & Girardeau, 1966) as part of their studies of the relationship between intelligence and learning. In general, these researchers have found that severely retarded persons can acquire complex skills that can be achieved within a reasonable training period and that can be retained and transferred to new situations.

Learning principles and methods developed in laboratory settings have been applied in vocational and academic settings serving severely handicapped persons. The laboratory research derived from Zeaman and House's attention and discrimination learning theories has been extended by Gold (1972), and Close, Irvin, Prehm, and Taylor (1978) to the sheltered workshop. Basic research methods based on the operant model (Honig, 1966), have been extended by Sidman and Cresson (1973), Guess, Sailor, and Baer (1974), and Fink and Brice-Gray (1979) to reading, language and problem-solving functions.

Methodological approaches to the study of severely retarded persons began with a medical perspective that emphasized description, etiology, treatment of physical conditions, and primary prevention. As methodological approaches evolved, they have increasingly reflected a broadened psychological perspective derived from behavioral research with emphasis on pushing back the limits of behavioral development and functioning.

Recent Research with the Severely Mentally Retarded Persons: A Social Ecological Perspective

The behavior and development of retarded persons is a function of individual differences and of the physical and social characteristics of their environments. There is a transactional reciprocal interplay among biology-environment, person-person, and person-environment interactions that can facilitate or delay development (Switzky & Haywood, 1984). To facilitate the development and learning of retarded persons, practitioners must seek an optimal match between persons, including their psychological and biological components and their social-ecological settings, including physical and social-ecological components (Haywood, 1981). These matches between (retarded) persons and settings are not permanent but need to change as the developmental needs of persons change and they are brought into less restrictive, more enhancing, more demanding environments (Haywood & Newbrough, 1981). Programs of developmental intervention for mentally retarded persons should focus as much on the characteristics of personnel, including teachers, surrogate parents, caregivers, and other professionals, and on the characteristics of settings, as on the characteristics of mentally retarded persons. Thus both the unique qualities of persons and the characteristics of settings can be manipulated to facilitate optimal person-environment congruence.

The Search for the Optimal Environment

There is a considerable literature on the effects of living environments on the growth and development of retarded persons, including those who are the severely retarded (Bruininks, Meyers, Sigford, & Lakin 1981; Heal, Sigelman, & Switzky, 1978). Large institutions still provide care and treatment for significant numbers of severely retarded persons (92 percent of profoundly retarded and 32 percent of the severely retarded (according to Eyman & Miller, 1978). However, increasing numbers of severely retarded persons are living in their family homes or in community group homes. What are the characteristics of the optimal treatment environments for severely retarded persons that will facilitate quality care and personal development? As in most areas of research involving severely retarded persons, the answers are fragmentary and less than clear (see Butterfield this volume). Balla (1976) has suggested four dimensions by which quality of care may be measured: (a) quality of life as defined by resident care practices involving "care," "services provided," "child-orientation vs institution-orientation" (King, Raynes, & Tizard, 1971) and satisfaction of residents as well as the quality of transactions between clients and important persons in their lives; (b) actual behavioral functioning of residents; (c) the extent to which the residence promotes the independence of the participants, and (d) the extent to which the residence promotes and facilitates involvement in the community.

Even though Balla (1976) concluded that resident-care practices appear to be more resident-oriented in smaller, community-based facilities than in large institutions, he emphasized that it is the *type* of institution rather than its size that is the primary determinant of resident care practices. Similar points are made by Butterfield (this volume). While many large institutions do provide poor quality of life experiences for retarded persons, this does not necessarily mean that smaller facilities, even in community settings, provide better quality life experiences. Life in group homes may be just as demeaning and restrictive as life in large institutions (Balla & Klein, 1981). Lakin, Bruininks, and Sigford (1981) have argued that the size of a residential facility may indirectly influence its organization and the interaction between residents and caretakers. King, Raynes, and Tizard (1971) found a strong relationship between the child-orientation of a facility and its organizational structure. In child-oriented units, there was less division of labor, more direct involvement with the children by supervisors, more program autonomy at the living unit level and more flexibility in terms of staff scheduling. King et al. (1971) found that staff inservice training practices (child-orientation vs institution-orientation), appeared to be responsible for these variations in interactions between caretakers and residents. The absolute size of a facility or its placement in the middle of a community or in a rural setting, does not affect the child-orientation of a facility as much as it affects organizational structure and staff-training practices, which in turn affect the outcome of its orientation toward residents. In terms of actual behavioral functioning and behavioral development of residents, the evidence as reviewed by Balla (1976) and Balla and Klein (1981) does not firmly support the notion that family environments promote greater behavioral development than do institutional environments, or that small community-based facilities are more effective than large central institutions.

Contrary to many peoples' expectations, there is considerable evidence that placement in the large institution can be beneficial for retarded persons (Balla & Klein, 1981; Balla, Butterfield, & Zigler, 1974). The preinstitutional environments of retarded persons in such cases may have been so deleterious that placement in the less-than-adequate environment of the large institution was a substantial improvement.

With respect to the goal of independence and facilitating involvement in the community, it has been in recent years almost an article of faith that living-settings in the community and close to the family residences of clients must be considerably more beneficial than living settings that are away from community facilities and family residences. Currently available evidence (Butler & Bjaanes, 1977, 1978) does not support the notion that closeness of potential community facilities or the potential closeness of family members bring *automatic* developmental benefit to retarded persons. Such concerns need to be an *explicit part* of therapeutic programs. If community care facilities are to provide normalizing environments, attention must be paid not only to their location, but also to qualifications of service providers, administrative structures, the nature and extent of internal programs, exchanges with the attitudes of the community and those of staff members, utilization of available community programs, and the match between personal needs and assets on the one hand and the demands and supports of social and physical environments on the other.

Methodologial Concerns: Social-Ecological Perspective

There is an almost endless supply of research questions as well as methodological problems concerning issues in the development and habilitation of severely retarded persons. Appropriate and completely useful operational definitions for our notions of adaptive behavior, normalization and adjustment have yet to be developed. These notions are imprecise, complex and vary from time to time, and from one area of life to another (Edgerton, 1981). The majority of studies of the effects of living environments on the growth and development of retarded persons have been done with mildly and moderately retarded persons. Little has been done with severely retarded groups. Such research as has been done has been broad in scope, often retrospective, episodic, cross-sectional, brief in duration, and with measurement of dependent variables on only one occasion rather than repeatedly. Few of the studies were longitudinal and individuals were not randomly assigned to different living units because the studies were mostly non-experimental (Butterfield, this volume). In the future, investigators should assess via direct observations in the natural living environments exactly what is happening to retarded persons over long periods of time. We need studies (Landesman-Dwyer, Stein, & Sackett, 1978) that are: (a) prospective, with observation of clients over time in at least two different environments; (b) broadly comparative, taking into account the natural variations that occur within any set of generic services (e.g., compare several different institutional settings and an equal number of varied community residences); and (c) at least partially experimental, allowing for some controlled manipulation of the environmental variables that appear to be critical in determining "success."

Are researchers restricted to microanalytic quantitative observational studies or is there room within the scientific enterprise for more qualitative approaches? Are research techniques such as participant observation, or depth interviewing, or the study of personal documents, legitimate scientific methods? Qualitative analytic techniques focus on the perceived world views of the retarded persons themselves in the context of their past and present situations. Such techniques may be less valuable when applied to the world of the severely retarded than to less retarded persons, but nevertheless, these techniques may be useful in understanding how retarded persons view their worlds, and why retarded persons behave as they do. Qualitative research techniques have not been as refined and systematized as other research approaches, but this is changing, and an up-to-date methodology does exist (Bogdan & Taylor, 1975; Edgerton & Bercovici, 1976). Taylor and Bogdan (1981) have pointed out the need for qualitative research with persons labeled severely mentally retarded.

> We must be rigorous in our attempts to develop techniques to understand the subjective state of those we have traditionally considered as being impossible to understand. If we have not understood the severely disabled person, it is because we have not really attempted to so do. The problem is ours and not theirs (Taylor & Bogdan, 1981).

Qualitative research techniques can be useful in helping understand how retarded persons perceive their living environments, how community residences are different from house-living settings, and from large institutions. Qualitative research techniques may allow us to understand the perceptions of caretakers, parents, relatives, teachers, professionals, and ordinary citizens, toward persons defined as mentally retarded and how and why these persons interact with retarded persons as they do. A good example of the use of qualitative mental retardation research is the work of Heshusius (1982).

There is little literature documenting how to facilitate the developmental progress of absolute profoundly mentally retarded nonambulatory persons. Examination of what literature does exist gets one involved with the issue of the extent of the trainability of severely and profoundly retarded persons. Some investigators (Kauffman & Krause, 1981; Ellis, 1981) believe that historical and contemporary attempts to educate the absolute profoundly retarded have not been fruitful and that training of useful and sequential behavior may be impossible. Other investigators (Baer, 1981; Menolascino & McGee, 1981) believe that we are on the right track in terms of developing training procedures and it is only a matter of time before a breakthrough emerges. The trainability issues will be discussed later.

Learning in Severely Retarded Persons

Until a few years ago, most experts believed that severely mentally retarded persons were capable of learning only the most rudimentary of skills. Profoundly retarded persons were viewed as totally intractable. These ideas were based on the following assumptions: (a) the many organic deficiencies that severely retarded persons manifest also restrict their intellective capacities and potential for habilitation as measured by their low IQs; (b) since there is a direct relationship between present behavioral deficiencies and future behavioral development, persons who have greater behavioral deficits also have less potential for future behavioral development; (c) persons who show minimal progress when placed in the usual educational environment probably are incapable of learning no matter what educational or environmental interventions are tried; (d) since such persons meet the diagnostic criteria for classification as severely retarded, they are essentially like all other persons in that class, i.e., individual differences must be neither large nor important. These ideas have influenced policy decisions concerning the types and extent of educational and habilitative services offered to severely retarded persons and such services are often limited. In contrast to these totally pessimistic assumptions, applications of behavior modification technology have demonstrated numerous instances of behavioral improvement and acquisition of a variety of skills in domains which make up "activities of daily living" or adaptive behavior (Ellis, 1979; Matson & McCartney, 1981; Sailor & Guess, 1983) for some severely retarded learners.

What is the evidence regarding the success of operant-based behavior modification programs? Most researchers would probably agree that the current literature shows that some skills can be taught to some low-functioning retarded persons. Some profoundly retarded persons can learn some particular skill to some level of mastery. The durability of the training over time, as well as the extent to which the training will generalize over settings, persons and conditions is largely unknown. Available evidence does support the notion that many children and adults of very low intelligence could be successfully trained. Baumeister (1981), in a discussion of the value of behavior modification for the severely retarded, has argued that behavior modification technology represents the most useful instructional approach presently available; however, the effectiveness of these techniques to generate useful, durable, sequenced, generalizable behavior has been "grossly exaggerated" (Ellis et al., 1981). Behavior modification procedures for the severely retarded, Baumeister (1981) argued have to be evaluated in terms of: (a) the level of performance aspired to; (b) the difference between the behavior in question before and after training; (c) the costs relative to benefits; (d) the social significance of the behavior; (e) the durability of the training; (f) the generalization achieved; and (g) the resources available. Thus the effectiveness and value of behavior modification training depends on the values of the persons conducting the program, the values of the families receiving the program, and the values of the agency paying for the program. Many experts regard the current state of affairs as a methodologist's nightmare (Baumeister, 1981; Ellis, 1981; Whitman & Scibak, 1979).

What are the methodological considerations that need to be investigated to improve the scientific quality of behavior modification research with severely mentally retarded persons? Whitman and Scibak (1979, 1981) have suggested the following:

1. *Increase reliability of measurement.* Current researchers need to assume that their measurement systems may accurately represent the behavior of the person being observed rather than errors in the rating instruments or errors in the observers themselves.

2. *Increase internal validity.* Researchers need to examine the functional relationships between treatment procedures and changes in behavior by use of appropriate experimental designs to assure the systematic introduction of the treatment rather than some uncontrolled aspects of the study producing the observed change in behavior. Researchers need to be cognizant of the limitations of single-subject designs. If comparisons of different techniques as well as the component analyses of treatment packages are to be conducted, single-subject methods will probably have to be abandoned and replaced by group designs that make much greater demand on time, money, and the availability of subjects.

3. *Response change assessment.* Ideally a treatment should produce generalized change in a client's behavior over time, over situations, and in other forms of behavior. Researchers need to test explicitly for duration of training effects over time. Researchers need to test as well for situational generalization effects by observing the subjects target responses in the treatment settings, before, during, and after treatment as well as doing the same thing for target responses in untreated situations. Treatments should change behavior in the treatment setting, and in more natural settings. Ideally, treatments should not only change the behavior that was the focus of treatment, but should also change some forms of behavior that were not specifically the focus of treatment, such as increasing other appropriate behavior, or decreasing other maladaptive responses. Unfortunately, only rarely is there extensive assessment of generalization effects in behavior modification studies with severely retarded persons.

4. *External validity.* Questions of external validity have to do with the generalizability, or exportability, of an experimental process to situations, settings, therapists, and populations beyond the immediate locus of the experimental situation. Would behavior modification experimental manipulations be replicable if similar subjects, therapists and environmental circumstances were used? Generally speaking, single-case designs lack the requirements for external validity (Hersen & Barlow, 1976).

Often studies, especially those involving severely retarded persons, employ very few subjects, only vaguely describe their target populations, often blurring the heterogeneous learning characteristic known to exist among severely retarded learners (Switzky, Haywood, & Rotatori, 1982), fail to describe in sufficient procedural detail the intervention used or the types and characteristics of the persons conducting the intervention or their training, or the types of treatment environments used. As a result, it is not always possible to conclude that severely retarded persons, in *general,* will respond to a particular treatment. It is necessary that random subject selection procedures be used or to make explicit how subjects were chosen for experimental inclusion. It is impossible for a teacher of severely or profoundly retarded students to know whether a particular experimental treatment will be suitable for his or her students specifically, or the environmental circumstances or even exactly what the intervention was or what training is necessary to carry out the intervention, because such information is not mentioned in the article.

With respect to the external validity of single-subject experimental designs, Hersen and Barlow (1976) have stated that isolating the active therapeutic variable for a given client through a vigorous single subject experimental design provides little basis for inferring that this therapeutic procedure would be equally effective when applied to clients with similar behavioral disorders (client generality), or when applied by different therapists (therapist generality), or when applied in different settings (setting generality). Because of these problems associated with generalizing from a specific case, group designs and extensive replication of single-subject designs with similar clients and identified target behavior needs to be done. In systematic replication of single-subject designs, the original intervention can be replicated while varying the setting, the behavior change agent, the type of client, or all combinations of these parameters. Systematic replication effects can increase the external validity of an intervention; however, such attempts are rare. Matson, Ollendick, and Adkins (1980) have recently undertaken a group study with severely retarded persons to evaluate dining room and eating behavior with a 4-month follow-up. Thus attempts to increase the external validity of behavior modification studies by the use of group designs and long-term follow-ups are beginning to happen.

Research, Policy Decisions, and Programming

Research on mental retardation and the formulation of public policy concerning retarded persons have rarely enjoyed a close and predictable relationship (Haywood, 1981). The formulation and implementation of public policy are political processes, not scientific ones. Science is often influenced by variations in public policy (most obviously by the ups and downs of research grant funding—see Baumeister & Berkson, 1982), less frequently, the reverse is true that scientific studies shape policy.

In spite of an often tenuous relationship between data and policy, there have been positive outcomes for mentally retarded persons in some instances of data-based public policy. Examples include: (a) mandatory neonatal screening for phenylketonuria in most of the 50 states has significantly reduced the incidence of PKU; (b) changes in state abortion laws have reduced the incidence of Down syndrome.

The other side of the picture is that many sweeping changes have been advocated, and some made, in the absence of relevant data when in fact such data would have been relatively easy to get. The aggressive movement to completely eliminate residential institutions is not based on relevant data, but instead is part of the sociopolitical movement that is fueled by philosophical principles. Relevant data on that issue would have to include not only evidence that institutions have negative effects on the development of retarded persons, or at least that they do not have sufficient positive effects to justify the inherent restriction of liberty that is by definition part of institutionalization, but also that some of the various alternatives to institutionalization have more positive or fewer negative effects. Such data are not yet available. In the same way, policies dictated by the courts on modes and levels of "programming" (i.e., structured and developmentally purposeful activity) are based less on data than on nonempirical assumptions, hope and philosophy. Yet, relevant data could be gathered, at some expense.

In view of the rather sad state of the relationship between research and public policy in the care, treatment, education and habilitation of severely retarded persons, we want to suggest that researchers keep a policy goal in mind and ask themselves, when designing studies, what changes could be made that would increase the policy relevance of their research. A sample of policy-relevant research strategies would include: (a) greater attention to individual differences, including specification of the characteristics of those subjects in the samples who did not behave according to expectation; (b) replication across settings; (c) greater emphasis on field settings, where one is likely to encounter interactions among influencing variables that are controlled or ignored in laboratory settings; (d) more extensive use of observational methods, in recognition that people often behave in ways not anticipated by experimenters; (e) more extensive use of nonexperimental criterion variables, such as teacher satisfaction with intervention methods, parent response, subjective reactions of the clients themselves, cost (and therefore the reactions of administrators); and (f) effects of particular treatments on other dependent variables not considered theoretically to be directly influenced by the treatments.

Promising Recent Strategies and Anticipated Trends in Research

Many new lines of research that may help to facilitate the development of severely retarded persons are emerging and it would be impossible to treat all of them here. Trends in new research areas to be reviewed focus upon understanding the relationship between the biology of the organism and the use of behavioral principles to ameliorate some maladaptive behavioral states associated with severe mental retardation, and using advanced electronic technology to facilitate the learning, communication and the motivation of severely retarded persons.

MSH/ACTH Neuropeptide Fragments and Mental Retardation

Peptides are short chains of amino acids, found in the brain and bloodstream, that have important physiological and behavioral effects. MSH (melanocyte stimulating hormone) is a peptide that causes color change in frogs and lizards and is present also in the human brain. ACTH (adrenocortotropic hormone) which stimulates the release of corticosterone from the adrenal gland, and MSH have amino acid sequences in common (4–10), which seem to be responsible for the facilitation of attention involving visual retention, decreased anxiety and enhanced visual discrimination when injected in human beings (Sandman, George, Nolan, van Reizen, & Kastin, 1975).

The effects of MSH/ACTH 4–10 peptide fragments have also been investigated in mentally retarded persons. Sandman, George, Walker, Nolan, and Kastin (1976) found that injection of MSH/ACTH 4–10 peptide fragments in moderately retarded men, 20–42 years of age, recruited from a sheltered workshop, had the following effects: (a) significant orienting responses to novel stimulation, as measured by deceleration in heart rate; (b) improved learning of intradimensional, extradimensional, and reversal shifts in visual discrimination problems; and (c) improved visual retention, spatial location, and auditory pattern matching, as assessed by the Benton Visual Retention Test, and the Halstead-Reitan neuropsychological battery. These results support the idea that the MSH/ACTH peptide fragments enhance attention. The study was repeated with an analogue of MSH/ACTH 4–10 which was 1000 times more potent than the original parent peptide and could be taken orally (Walker & Sandman, 1979). This study showed similar, but not as dramatic effects as the first study, because presumably too high a dose of the drug was used. A third study was performed (Sandman, Walker, & Lawton, 1980) with the oral analogue of MSH/ACTH 4–10, that demonstrated a differential dose effect on the productivity of moderately retarded sheltered workshop workers. Intermediate levels of the peptide facilitated productivity and concentration, and also increased interpersonal communication and gregariousness when compared to the placebo treatment.

These three studies demonstrated that neuropeptides can facilitate attentional processes in retarded persons, and that persons who are suffering from attentional deficits might benefit from treatment with MSH/ACTH 4–10 fragments and related analogues. Even though brain structures may be damaged (Walker & Sandman, 1979), behavioral deficits related to them may not be permanent and irreversible. Thus, it may be the interaction of dynamic biochemical processes and brain structures that determine behavior. The administration of the appropriate neuropeptides should ameliorate specific behavioral deficits. For the severely mentally retarded, further research may reveal the degree to which MSH/ACTH 4–10 neuropeptides and their analogues can ameliorate attention deficits.

Beta-Endorphins and Self-injurious Behavior

Endorphins are neuropeptides found in the brain that exert morphine-like analgesic effects. Sandman, Datta, Barton, Hoehler, Williams, and Swanson (1983) had speculated that self-injurious behavior in developmentally disabled persons may be due to a disruption of their endogenous opiate system. Persons having self-injurious behavior (SIB), may have an overabundance of B-endorphins which restrict attention and perception and raise pain thresholds (hyperalgesia). SIB may be maintained by the attempt of the person to increase their level of stimulation and to maintain the euphoria associated with opiates. SIB may be a symptom of addiction to endogenous opiate-like substances (B-endorphins). Injection of an opiate antagonist such as naloxone may compete for the opiate-reception sites in the brain, thus attenuating the effects of B-endorphins in the brain and reducing the SIB. Sandman et al. (1983) injected naloxone into two profoundly retarded adults with severe SIB. Naloxone ameliorated the severity of SIB over a short period compared with a placebo control condition. Davidson, Kleene, Carroll, and Rockowitz (1983) extended the Sandman et al. (1983) study to a multiply handicapped severely retarded boy. Though the frequency of SIB did not change, the quality of SIB became less intense. The control of SIB in severely retarded persons by the use of opiate-antagonists like naloxone and its analogues (e.g., naltrexone) needs further investigation, since SIB occurs frequently and are a resistant problem in severely retarded persons.

Kastin and Sandman (1983) have speculated that MSH/ACTH 4–10 and the B-endorphins may be involved in a self-regulatory system because they act in opposition to influence behavior. MSH/ACTH 4–10 may operate to improve attentional processes whereas the B-endorphin may operate to restrict attentional processes. Further, it has been demonstrated that MSH stimulates fetal growth and brain development in immature organisms and that the fetus is exposed to high levels of MSH just prior to birth. Fetal stress elevates B-endorphins, and high levels of B-endorphin delay development in rats. During normal birth, MSH and B-endorphins both rise, and MSH may moderate the effects of endorphins in the infant. In a traumatic birth, only the levels of endorphins may rise precipitously, resulting in poisoning and a developmental disorder in the infant. The study of the interactions between B-endorphins and MSH/ACTH 4–10, especially in conjunction with behavioral principles, may have significant implications in preventing and ameliorating behavioral deficits associated with mental retardation. As Sandman (1983) has speculated, the brain's own chemical products may prove to be self-correcting factors that can dramatically change or reverse the brain's own structural or functional deficiencies. Research on the biochemical process underlying behavior may have tremendous implications for ameliorating some of the behavioral deficiency observed in severely and profoundly retarded persons.

There are several methodological problems confronting researchers interested in investigating the effects of drugs on the brain and behavior of persons. They include: (a) large individual differences that exist in reactivities to drugs; (b) the unknown therapeutic dose and durations of drug effects; (c) the intervention of therapeutic drug effects with current environmental events and learning histories of persons; (d) the need for placebo control groups who do not get any active drugs; and (e) the need for double-blind experimental designs, where neither the subject nor experimenter knows who receives the active drug.

Use of Microcomputer Technology

Microcomputers and their evolving technology may prove to be extremely important to severely retarded learners. The power of the computer to facilitate instruction is evolving. Computers can be used as communication aids, and as a means to help severely retarded persons compensate for their devastating impairments by extending their abilities to enable them to gain more control over their world, and thus to be more competent and less helpless. Extensively physically handicapped learners, by the use of transducers sensitive to eye and head movements, sucking behavior, or muscle twitches, can control electronic circuits that can be used to activate radios, televisions, lights, or appliances. Brinker and Lewis (1982) have developed a contingency intervention system for handicapped infants by which these infants learn that their behavior makes a difference and that they can control important contingencies in their world. Handicapped infants can learn by kicking a panel, or moving a switch with their arm, to turn on a tape recorder, to activate a battery powered train, or to see pictures of faces. Thus, microcomputer technology can help facilitate the intrinsic motivation to explore and to learn, which in many cases is at a low level in severely retarded learners.

Microcomputers may provide communication enhancement for nonverbal preliterate learners. For students familiar with Bliss Symbols, computerized talking portable lap Bliss Boards have been developed such as the Semantically Accessible Language Board (Eulenberg & Rahimi, 1978), which permits nonverbal learners to synthesize English speech from the Bliss Symbols. Microcomputer-based communication aids such as the Phonic Mirror Handivoice, the Talking Typewriter, and Type-N-Talk, have been developed (Bennett, 1982; Foulds, 1982). The Phonic Mirror Handivoice is a portable speech synthesizer that is activated by entering a three digit code on a pad. The student types English words onto the key board and the Talking Typewriter computer translates them into English speech. The Type-N-Talk microcomputer translates to speech any English text typed into the microcomputer. Portable battery operated microcomputers are now available, such as the Panasonic Handheld Computer, which can be used to enhance communication for the handicapped when connected to the Type-N-Talk. Further research is needed to determine the value of this microcomputer technology in developing useful expressive communication systems for severely retarded learners.

The use of the microcomputer technology in instruction may be valuable for severely retarded learners as well. The Kurzweil Reading Machine (Kurzweil Computer Products, 1979) can convert printed material to English speech, and thus facilitate learning in severely retarded persons. A technology for teaching using microcomputers and video discs, the Intelligent Videodisc for Special Education Technology project, IVSET (Allard & Thorkildsen, 1981), has been developed which allows learners to interact with instructional programs. IVSET provides a curriculum in basic skill areas such as shape, size and color matching, telling time, and word recognition. The student interacts with the instructional program by touching the television screen. The system can sense the student's responses and can provide almost immediate feedback and branching. More typically, the microcomputer, when hooked up to a floppy disc can provide drill and practice programming, interactive tutorial activities, simulation of real phenomena and problem solving activities. The application of computer assisted learning to the problems of the severely retarded is in its infancy, but offers promise as an instructional strategy.

SUMMARY

Over the last 30 years, research with severely mentally retarded persons has shifted from a biomedical perspective concerned with describing disease states, to one interested in facilitating behavioral and psychological development, as well as educational treatment using behavioral, biological, and technological methods. We believe that researchers concerned with the problems of the severely mentally retarded should take a social-ecological perspective, which is concerned with elucidating the transactional reciprocal interplay among biological-environmental, person-person, and person-environmental interaction that can either facilitate or delay the development of retarded persons. We have reviewed literature relating to the effects of living environments on the growth and development of retarded persons, and concluded that living settings that are more resident-oriented in their care practices constitute a more development enhancing environment. Research methods based on qualitative analytic approaches, including participant observation, depth interviewing, and the study of personal documents, may extend our understanding of the world of retarded persons and may be a valuable addition to the usual quantitative micro-analytic approaches. Over the last 30 years, it has been demonstrated that the learning abilities of severely mentally retarded persons are much greater than was previously believed, with behavior modification technology providing the most effective behavior change and teaching strategies. Research methods that can elucidate questions of external validity concerning the generalizability of experimental processes to situations, settings, teachers, and populations beyond the immediate locus of the experimental situation would be a valuable addition to the literature.

Only a few instances of public policy regarding severely retarded persons having been determined or even strongly influenced by knowledge gained from existing research, although some of these few instances are positive and dramatic. More often, policy decisions are made on the basis of inadequate or no data, sociopolitical and philosophical positions, the influence of pressure groups, and even fads. The relationship between data and public policy would probably be stronger and healthier if researchers would adjust their studies to take account of long-range policy goals. Designs toward this end might include: emphasis on individual differences; replication in different settings; research in field settings; use of observational methods; careful selection of criterion variables. New lines of research that may have implications for facilitating the development and educational skills of severely retarded persons include the study of biochemistry of behavior, e.g., MSH/ACTH neuropeptide fragments and B-endorphins, and the use of the evolving microcomputer technology in the development of teaching systems and for communication enhancement.

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